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ABSTRACT

The fourth edition of the sourcebook, "Reinventing Quality," contains descriptions of innovative activities designed to assure and enhance the quality of services to persons with developmental disabilities. The programs profiled are those seen as: systematic efforts to improve the quality of services to persons with developmental disabilities, containing elements that may be replicable elsewhere, likely to be of broad interest, and not redundant of other programs described. Programs include efforts to support the redefinition, assessment, and/or enhancement of quality in community services. The programs are subsumed under the following broad categories: statewide information and evaluation systems, service agency development, system-wide quality enhancement, values infusion, consumer and citizen monitoring, community relationship building, technical assistance, personnel training and professional development, advocacy training and support for individuals and families, best practices, and quality assurance in Medicaid Community Supported Living Arrangements programs. Direct service programs are not included. A paper by Clarence J. Sundram titled "Quality Assurance in an Era of Consumer Empowerment and Choice" introduces the sourcebook. (Contains 37 references.) (JDD)

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Reinventing Quality

A Sourcebook of Innovative Programs for Quality Assurance and Service Improvement in Community Settings

1994 (Revised) Edition

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Research and Training Center on Residential Services and Community Living
Institute on Community Integraton (UAP)
The College of Education
UNIVERSITY OF MINNESOTA

Reinventing Quality

A Sourcebook of Innovative Programs for Quality Assurance and Service Improvement in Community Settings

1994 (Revised) Edition

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Revised November 1994

Report 43

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PREFACE

In December 1992 a national conference to examine selected efforts by states to ensure and enhance the quality of services provided to persons with developmental disabilities was held in Alexandria, Virginia. The conference was co-sponsored by the National Association of State Directors of Developmental Disabilities Services and the Research and Training Center on Residential Services and Community Living, Institute on Community Integration (UAP), University of Minnesota.

A sourcebook, *Reinventing Quality*, containing brief descriptions of innovative quality enhancement efforts by conference presenters and others was prepared for the 1992 Alexandria conference by the Research and Training Center. A revised and expanded version of the sourcebook was published by the Center in June 1993. In February 1994 a third version of *Reinventing Quality* was published to coincide with a national conference, held in Hollywood, Florida and co-sponsored by the American Network of Community Options and Resources and the Research and Training Center, on cooperative efforts by states and private service providers to improve service quality for persons with developmental disabilities. This, the fourth version of *Reinventing Quality* revises and expands previous descriptions of exemplary activities to assure and enhance the quality of services to persons with developmental disabilities.

Background:

Recent years have seen a shift in long-term care for persons with developmental disabilities from large institutions to community settings. But people receiving community services can fully realize the potential for improved quality of life afforded by this movement only if quality assurance expectations and activities are changed significantly from those originally developed for institutional care.

While the nature of efforts to improve the quality of community services varies among and within states, recent years have brought many demonstrations of innovative and comprehensive quality assessment and enhancement practices. This sourcebook has been developed with the assumption that knowledge of and contact with such efforts may help others to fashion their own responses that not only protect the basic safety and well-being of individuals, but also encourage and support their preferred choices, personal growth, and individual lifestyles.

It is anticipated that this sourcebook will continue to be published periodically for the foreseeable future. You are invited to nominate innovative and exemplary quality related efforts for possible inclusion in subsequent versions of the sourcebook. To do so write to the Editor, *Reinventing Quality*, or phone (612) 624-8246.

Method:

In compiling the first sourcebook, the Research and Training Center invited state directors of developmental disabilities services, executive directors of state developmental disabilities councils, managing attorneys of state protection and advocacy agencies, and a number of others with special knowledge and interests to identify innovative and exemplary programs that were designed to improve the quality of services to persons with developmental disabilities. A number of programs were identified.

Following on those referrals, key informants in each program were identified and interviewed by Center staff who then drafted a brief summary of each program selected for inclusion. The sourcebook does not include descriptions of "exemplary services" per se. Activities described are those seen as: a) systematic efforts to improve the quality of services to persons with developmental disabilities; b) containing elements that may be replicable elsewhere; c) likely to be of broad interest; and d) not redundant of other programs described. After review by key informant(s) for each program the summary descriptions were included in the publication. Efforts to identify programs for each new version have involved contacts with an increasing number of sources (e.g., service providers; advocacy organizations, other readers of previous versions). With each new version programs included in previous versions are updated in following versions. With these exceptions, the procedure has remained constant.

Content and Organization:

Programs profiled in this sourcebook include a variety of efforts to support the redefinition, assessment and/or enhancement of quality in community services. Direct service programs, however, are not included. The programs and activities described have been subsumed under broad categories including:

1) statewide information and evaluation systems,
2) service agency development,
3) system-wide quality enhancement,
4) values infusion,
5) consumer and citizen monitoring,
6) community relationship building,
7) technical assistance
8) personnel training and professional development,
9) advocacy training and support for individuals and families,
10) best practices, and
11) quality assurance in Medicaid Community Supported Living Arrangements programs.

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The writers wish to thank the state directors of developmental disabilities services, the managing attorneys of protection and advocacy agencies, the executive directors of state developmental disabilities planning councils, ANCOR members, NASDDD members, and all others who submitted suggestions of programs for inclusion in the sourcebook. Thanks also go to the contact persons listed for each program profiled in the sourcebook. They provided the RTCRSCL with valuable information and updates on their quality enhancement initiatives.

Without the aid of RTCRSCL staff, including Laura Lafrenz, Noelle Knapp, and Cheryl Morgan the authors could not have published this sourcebook. The writers appreciate their help in editing, wordprocessing, and providing suggestions.

Partial support for the development and dissemination of this report was obtained from the National Institute of Disability and Rehabilitation Research (H133B30072) and the Administration on Developmental Disabilities (90DD0180), with supplemental assistance from the Health Care Financing Administration.

QUALITY ASSURANCE IN AN ERA OF CONSUMER EMPOWERMENT AND CHOICE

By Clarence J. Sundram*

I realize that some of you received copies of the Reinventing Quality sourcebook which contained the speech on Reinventing Quality Assurance that I delivered last year.

For those of you who didn't read my last speech, let me give you a short summary of the key points:

First, it is premature to talk of reinventing quality when it hasn't been invented in the first place. Rather, what we have been engaged in for the last couple of decades is borrowing from manufacturing industries methods of assuring quality and force fitting them into a human service system. The resulting application of mechanistic standards and rigid processes has created a lot of work but diverted our attention from a search for quality which includes a large dose of customer satisfaction.

Second, more fundamentally, QA systems have generally failed to recognize the way in which bureaucracies work, and have therefore had limited ability to deal with the most serious quality problems. Most QA systems don't have the license and thus are rarely are willing to confront a superior with truths that fundamentally challenge the wisdom of existing programs and practices. I can't tell you the number of times that QA staff have called my agency because they feel that they cannot report real problems they are encountering through official channels within their agencies.

A useful way to understand how most QA systems operate is to consider the difference between what Harvard Professor Christopher Argyris calls "single loop" and "double loop" questions. "Single loop" questions work pretty much like a thermostat which is set at 70° and checks the temperature and turns the heat on and off. A thermostat cannot, however, question the wisdom of its programmed temperature -- which requires a double loop question.

QA systems spend most of their time and energy on single loop questions. They can become reasonably effective in checking whether programs comply with standards and regulations, but they are generally not designed to ask whether the standards or regulations bear any relationship to quality, or whether ensuring compliance is an effective means of promoting quality. Quality assurance systems were never designed to ask these "double loop" questions about the underlying values that guide everything we do. Indeed, when it comes to "double loop" questions that fundamentally challenge the wisdom of policies, some QA systems are expected to behave like the three monkeys of fable: "See no evil, hear no evil, speak no evil."

What we are beginning to understand is that the heart of quality lies in the double loop question -- is the effort producing the outcome that was sought, not whether every step was carried out as designed. When we focus on the outcome, it becomes clear that there are many paths to reach the destination, and that the regulatorily prescribed one is not necessarily the safest, most direct, the most scenic or the most comfortable for everyone or the one they would choose. There is real wisdom in that understanding as it frees us from self-imposed regulatory constraints that once may have had a purpose but the purpose has been overtaken by changes in the field. How many of us know people who are sent daily to day programs they dislike and provide them no benefit simply because the regulations require that they have a day program?

Third, the service system is undergoing a profound shift in thinking about the abilities, needs and aspirations of people with disabilities, and in the process is making significant changes

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in policy and practice away from the heavy reliance on rigid, highly structured residential and day programs, to adopting more flexible methods of supports tailored to the needs of the individual.

In this transition, there are seven key challenges to assuring quality that I would like to briefly discuss.

(1) Defining quality

What is quality anyway? Philip Crosby tells us that quality is "conformance to requirements; it is precisely measurable." But, as we are coming to realize, there is obviously a dimension to quality that applies to both manufacturing and even more so to the human services field, and that is that quality is what the customer wants. So, who is the customer?

(2) Identifying the Customer

If we look at the service system as it has existed to date, it is clear that the customer of the service system primarily has been the government agency that certifies, operates or funds the service system. Providers have had to satisfy the regulators and funders, not the people they serve.

A significant challenge we are going to have to confront on this journey to a new world of person-centered, preference-driven service/support system is deciding how do we truly make the person with a disability the customer whose expectations must be met as an essential component of quality? And how does the current provider-driven system, with its need for predictable budgets and revenues, accommodate to a world where the negotiations will occur not with a single state official for "beds" and "slots," but with dozens of consumers with their own ideas of what they want and are willing to pay for?

(3) Making choices real

I want to come back to this point a little later because I think this is one of the key challenges we face in this new vision of a more flexible, person centered, preference driven support and service system. We are all talking about providing choices so individuals with disabilities can express their personal preferences. It is a sound and important concept in public policy that takes more general notions about consumer participation to the next step of real empowerment. But there are land mines all around and we need to spend some time in thinking about how we navigate the minefield.

Just as consumer participation has often worked in practice to stifle the voice of the consumer, the same risk remains but now the stakes are greater. We also need to confront what limits a provider can and should place upon expressed choices.

(4) Good intentions are not enough

If you study history and the course of every reform in history, they all begin with good intentions by good people to do good things. And they all run into the very real problem of converting good intentions into reality. My father apparently once lived in hell (or maybe it was that we made his life hell) but he reported quite authoritatively that "the road to hell is paved with good intentions." Historians write about it more politely, by pointing to the constant struggle between conscience and convenience, with the compelling demands of convenience usually overwhelming the calls of conscience. We need to be keenly aware of this powerful historical reality, which is alive and well, as we consider the important reform ideas of today.

(5) More haste, less speed

Closely related to the issue of convenience are the risks entailed in taking ideas which work well on a small scale and in a carefully nurtured environment and extending them rapidly on a large scale to an unprepared environment. This is almost a prescription of how to kill innovations and reforms.

There is a hard lesson for those of us in the public sector that the very process of developing a large scale system to sustain innovation usually destroys it, particularly if you are under pressure to do it fast.

I think this lesson is particularly timely as communities across the country are implementing the newest innovation -- individual service environments under the Home and Community-Based

Waiver. Here again, the early reports are very encouraging. But in the fiscal environment which currently exists in most states, we can anticipate pressure to rapidly replicate and institutionalize the individualized service environment innovation to serve more people for less money. The risk is that in reacting to such pressures we may replicate the mistakes made by the mental health systems of this country of dumping people into communities without adequate services or supports or expectations for their safety and provide them with as little real choice as they now have.

A related risk, in taking an innovation that works on a small scale and spreading it to a larger environment, which requires a fundamental change in attitudes, thinking and behavior of a large number of people, is of simply changing language and terminology while leaving the underlying reality unaffected.

Language is easier to change than reality and long-ingrained bureaucratic behavior. We changed the group homes of the 60s into the Community Residences of the 1970s, which were converted into "community based ICF/MRs" in the 80s as we chased the medicaid dollar, and many are becoming IRAs under the Home and Community Based waiver in the 90s. The process of planning for them and of placing people in them hasn't changed essentially over that time, except that this time around services are being stripped away rather than added.

Senator Moynihan wrote an article in the American Scholar entitled "Defining Deviancy Down" where he essentially argues that we have surrendered in the battle against deviant behavior by progressively accepting more and more deviancy as the norm, requiring increasingly outrageous behavior to meet the definition of "deviant." I think a similar process is at work in defining "quality" down.

Quality is an aspiration to excellence much like an Olympian's level of performance. It is difficult to achieve and maintain consistently. Its very achievement re-sets the standard of aspiration --like the four minute mile or the seven foot high jump. In the human service field, we seem to be too caught up in attempting to make people feel good about what they do. Rather than inspire, lead or exhort them to produce their very best consistently in order to bask in the well-earned glow of accomplishment, we seem to have redefined quality to mean what is more readily achievable and praised what is ordinary. Defining compliance with minimum standards or survey findings of "no deficiencies" as "quality" cheapens the concept and robs it of value and its true meaning. We need to take a lesson from the field of weight control and understand the set point theory -- that every body has a set point at which it will remain without a massive and sustained effort to shift the set point. Making fundamental changes in the way services and supports are organized and delivered is like changing the set point.

(6) Who do you trust?

All of our observations over the past 15 years of studying programs and services in New York State and elsewhere show that what makes a difference between a good, a mediocre, and a poor program is not the model but the leadership and the people. Institutional wards have been found to provide caring and personalized environments which met many of the needs of the residents. Community residences and ICF/Mrs have done the same, as have family care programs, supported apartments and individualized service environments. And each type of program has also exposed people to serious harm, financial exploitation, abuse and neglect, sometimes resulting in death.

There are two central tasks to assuring quality. The first is clearly articulating the values and expectations that will govern all aspects of services and supports that are provided. In thinking about these values, the yardstick that seems indispensable is "are these values we would be willing to live our own lives by and to have guide the lives of our children?" Clearly these values ought to address the protective role of the system in assuring health and safety of all who are served. But they should also affirmatively address the promotive role of ensuring that people have the opportunities to live lives they want; to have autonomy in decision-making to the extent they are capable, and to have their decisions respected. And if this capacity is lacking, that proxies close to

the person -- parents, guardians, siblings, friends -- will be available to assist them in making decisions.

The second central task is to make a sustained effort to inculcate these values within the staffs of our agencies and within agencies we license or contract with to provide services and supports. We need to recognize that for many providers, provision of services and supports is a business and there is a continual tension between profit and care. We have seen in every regulated industry, including hospitals and nursing homes and mental health and mental retardation programs, profit-making and not-for-profit corporations,the hazards that exist when providers view people as commodities to whom financial entitlements are attached. After-the-fact monitoring may catch some of these providers, but usually only after they have inflicted substantial harm on vulnerable people. Thus, one of the most essential safeguards is to use an examination of character and competence of licensees to ensure that we do not entrust any agency or provider with responsibility for services and supports unless we are convinced, after a careful inquiry, that they embrace these values and would inculcate them in their staffs.

(7) Re-discovering common sense

I am in favor of a minimalist approach to regulation that relies heavily on common sense and professional judgment and less on detailed regulatory specifications. After two decades of experience with the existing regulatory system, it is abundantly plain that we have spent far too much time encouraging people to look at the ferns on the forest floor and have missed the forest itself. This tendency to drown both the regulator and the regulated in a mountain of data and an avalanche of paper seems to have clouded our vision rather than enabling us to see clearly what is going on, and to correct what needs to be fixed.

In my experience, I have found that, despite substantial regulatory interactions that providers have with state licensing agencies, they often respond much more speedily and concretely to a plain-spoken discussion of the aspects of their program that need attention. We need to find a way to replace fear-based monitoring, citations of deficiencies, and plans of correction with more collegial, supportive and assisting means of improving conditions that affect the every day lives of the people being served. And in looking for ways to enhance quality for the people being served, we ought not to overlook the obvious and fail to ask them what they want.

This common sense approach to quality assurance would also lend itself to increasing reliance on natural safeguards that exist in the community -- co-workers, friends, neighbors -- whose natural interactions provide the independent eyes and ears yet monitor unobtrusively.

The task of reinventing quality can be performed daily by observing and holding up a mirror to the system, to allow all of the stakeholders from the leadership of agencies, the consumers and providers, families and advocates, to see the reality and continually ask, "can we do better?"

In the end, people are protected and quality is assured less by formal systems of regulation and quality assurance activities than by a genuine commitment to excellence, by strong value based leadership in agencies and programs, by skill in infusing an organization with a sense of passion about the importance of its work in the lives of real people, and by the personal caring relationships that develop between the people being served and other people including family, friends, co-workers and people who work in this field. Ironically, what creates real quality is what is given freely and voluntarily rather than required by formal demands -- friendships, caring relationships, voluntary action to enter into the life of another for mutual benefit. This requires a greater degree of both freedom and choice for both the individual and the workers than is available. Failing that, attempts at quality assurance that continue to rely upon proxy measures are unlikely to produce quality or provide much assurance and they will remain an expensive choice of scarce resources.

It seems to me that in our quest for quality, we ought to focus more on finding ways to promote informed, voluntary choices of people with disabilities, to provide options that allow them to meet self-identified needs, and to promote opportunities for caring relationships to develop with people who are not also disabled.

These tasks are easier said than done. Yet, as we shift from a primary reliance on governmental monitoring and regulation to consumer choice and preference as means of promoting quality, it seems to me essential that we honestly ensure that we are eliciting authentic and informed choices of consumers, and that we adequately prepare everyone from agency managers on down for the new responsibilities they will have to shoulder in respecting these choices and, as importantly, in challenging them when they expose the individual to unrecognized dangers. The Boy Scouts motto: "Be Prepared" would be a good first step in today's Quality Handbook.

The preparation this time around is more complex than learning the regulatory requirements and black letter laws. Instead, we are entering a new world, like some of the private corporations that have prepared for a new world of business competition by throwing away their volumes of personnel manuals and replacing them with simple instructions like: "Employees are expected to use good judgment at all times." However, good judgment is a product of understanding the environment in which one is working, the values that are important, the risks that are present and the outcomes that are desired. People make good judgment when they are prepared for and understand the judgments they must make, and their responsibility to make them.

Why am I taking up your time to tell you what most of you already know? It is because I think we have tended to be seduced by the power of the new application to people with disabilities of old ideas of equality, choice, autonomy and inclusion to the point that we have relied more upon hope and belief than upon good judgment and careful planning to help make these ideas a reality. In the process, we seem to be replacing the old stereotype of people who are mentally retarded as hopelessly dependent, with a new stereotype of a rugged individualist, brave enough to cope with a hostile and dangerous world, if only given the chance. Both stereotypes contain serious misconceptions and fail to confront the reality that the class of people who are mentally retarded embraces a broad range of functioning capacity and includes people with significant areas of incapacity as well. Neither rigid notions of equality nor unbridled choice are likely to serve all people in this class well.

I believe that in the process of implementing these profound changes, we have not recognized this reality enough and have paid insufficient attention to the changing management and professional responsibilities that should accompany the new role of consumers. We have failed to squarely address the responsibility of people working in human service systems to safeguard people who may be endangered by their limited abilities and life experiences. And this failure to directly deal with these central issues of professional responsibility is manifesting itself daily in demonstrable harm to people who are mentally retarded. Why do I say this?

It is because what I hear and see on the frontlines of the services systems depict too many casualties of a failure to directly address the issue of professional responsibility in this age of person-centered, preference-driven service systems. Let me tell you a few of these tales from the frontlines about incidents that have occurred recently:

- A profoundly mentally retarded man was placed in a private home. It soon became apparent to staff from Protective Services that he was living in a small, filthy and barren room, spending his days semi-nude, sitting on a commode. His guardian appeared indifferent to his welfare. While professionals from several agencies dithered for a period of years about who should take responsibility, he suffered malnutrition, dehydration, decubitus ulcers and gangrene which eventually caused his death. The reason for inaction? A lack of clarity about legal responsibility for decision-making.

- Developmental disabled adults, exercising their right to procreate, are attempting to raise several children on their own. However, their limited abilities result in the children sometimes not getting sufficient food, health care or supervision. Parental frustration with their incessant needs sometimes results in abuse. Their case

manager has enrolled them in parent training programs, and arranged for home aides whose intrusion they resist. The pattern of problems hasn't changed much and the children are still periodically abused and neglected. But no one seeks protective services for the children because they don't want to turn their "client" in or risk them losing their children.

- In yet another case, a 40-year-old autistic, non-verbal man lived in a community residence and attended day programs. Staff supervised him carefully because he would constantly seek food and coffee, rifling through garbage, stealing others' food and drinking scalding hot coffee when he feared discovery. Once he learned to use transportation, he was allowed more freedom. He soon became a common sight in the community -- picking through garbage, begging, urinating in public places. He became an object of ridicule in the community and gained over 30 lbs. in a few short months. Professional staff took a hands-off approach to the developing problems, citing the "dignity of risk" in his new found freedom.

- A severely mentally retarded resident of a community program was heard screaming in his bedroom. When staff responded, they found him trapped face down between the mattress and the wall, with his underpants around his knees. He was yelling and crying and visibly angry as another resident was on top of him, pinning him down. The other resident's sweatpants were around his knees. This man has a history of sexual aggression against other residents and staff. Following staff intervention, they concluded that the incident was consensual, presumably because neither resident had been adjudicated as incompetent. Notably, staff concluded that neither resident had understanding about sexual activity nor would they respond to or benefit from sex education.

- Another severely retarded man, living in greater independence in a supported apartment, and finally free of a representative payee, spent his SSI check on crack, prostitutes and calls to a sex line. As a result, he didn't have money to pay his rent or to buy food for the month. The agency considered his non-payment of rent due to his poor money management skills as a choice. At first, they withheld his Personal Needs Allowance to pay back rent. But their eventual solution? Summary eviction from his apartment by placing all his belongings in garbage bags in the hallway. Presumably this was a lesson in normalization and consequences that, whatever its pedagogic value, left him homeless and broke.

These case examples can continue, describing people with severe disabilities living in the community in independent and sometimes unregulated settings, as part of this new movement to individualize supports. In some cases, we have seen people who are said to choose:

* to forego medical attention for serious and curable health problems; or

* to engage in dangerous, antisocial and sometimes criminal behaviors that jeopardize their freedom.

One of the bedrock beliefs about community living was an end to social isolation in an institution and the availability of the safeguard to be provided by different pairs of eyes, different relationships, different circles of friends and the protection inherent in each of these connections. When agencies have taken the time to work on community integration rather than community placement alone, they have found that this process works and helps enrich the lives of both the

individual being brought into the community and those around him. But it is a slow and intensive process, with large hidden costs in the time to develop and nurture these individualized connections.

When placements are made on a larger scale, especially under the pressure of court orders or budget cuts, as is more often the case, there is neither the time nor the fiscal luxury to invest in developing these highly individualized but essential connections.

In the cases I've described, the safeguards didn't work because the people had no real connections. In some cases, professionals who knew of conditions which endangered the individuals didn't intervene for fear of hurting their working relationships with other providers. In others, they did not intervene because they were genuinely unsure of their authority or responsibility, especially in the face of strongly expressed consumer choice. Worst of all, in some instances, local regulatory staff learned of the practices but also didn't blow the whistle or take action out of fear of surfacing problems with which the service system was unprepared to deal. (Inability to ask the double loop question.) Thus, not only did these practices go unchecked and uncorrected but, in a perverse way, they became precedents for acceptable conduct of staff working with vulnerable people.

You and I both know that choice was never meant to be the excuse for abandonment.

Choice was never meant to be a license for neglect.

Choice was never intended as a rationalization for abdication of responsibility.

But all these things are in fact happening in the name of choice. In the cases I have described and the countless others I am sure you can dredge up from your own experiences, the solutions aren't always self-evident. There are often no clear rules to follow, no regulations that prescribe action. But it is precisely this void that activates the responsibility that belongs to anyone professing to be a professional -- to apply a concerned judgment to the dilemmas presented in a changing world.

My point in calling attention to these cases is to note that the professionals involved in them were simply not prepared to take responsibility for the tangle of issues confronting them nor to aggressively seek their resolution. Instead, they found refuge in comforting shibboleths -- like the dignity of risk, the presumption of competence or the virtue of choice -- that excused their inaction, while doing nothing to protect from foreseeable harm the people they ought to have been concerned about. The service system itself, while spending a great deal of time in creating new service options, had nevertheless left them alone to wrestle with a world of changing expectations. And in "de-regulating" services as a reaction to the regulatory overkill of the ICF/MR era, the service system has largely eliminated clear expectations that people will be reasonably protected from harm, has delegated responsibility for monitoring back to the provider, and has almost insured its ignorance of any problems that develop.

We seem to have our own version of a "Don't ask, don't tell" policy. Commissioners and agency directors don't ask how their new polices may be adversely affecting the people being served. The front line staff and the case managers, both of whom play vital roles in enabling the promise of community living to be realized, seem to be learning a lesson that says "Don't tell" about things that go wrong because no one really wants to know. We cannot assure quality unless we are willing to deal not just with abstract ideas, but with the complex reality that these ideas produce.

In an era of individualized support environments, assuring quality will increasingly depend on the initial decisions about the nature of the living environment and the extent of the supports required for each person. The greater the degree of independence provided for the consumer, the less opportunity there will be for continued examination of the suitability of the extent of supports

to meet the person's needs. And if the supports and connections required for real integration are not carefully put in place, there is a risk that any harm that occurs will remain undetected.

Thus, inventing or reinventing quality means not only paying attention to consumer preferences, choice and satisfaction, but also carefully examining the decision-making knowledge and ability of the individual to assume the risks implicit in some choices.

While we need to maintain a decent respect for the right of people with disabilities to make the decisions they can, to quote Judge Friendly, we ought not to leave our common sense at the door when we go to work. People with severe cognitive limitations and limited life experience may want to make their own decisions and even believe they are making good decisions. They may unquestionably have the right, as we all do, to be dead wrong and make poor choices and mistakes, and hopefully to learn from them.

The greater the freedoms they enjoy, the greater will be the natural tension between their rights and the risks to them and to others involved in their lives, such as their children.

There are, unfortunately, no clear bright lines to demark the precise threshold at which outside intervention in their decision-making is acceptable or even obligatory for involved professionals. While laws define rights, they don't deal well with the ambiguity that is part of life. Thus, the legal process relies on the slow evolutionary method of case law to flesh out the contours of unclear legal obligations.

But you who run agencies and programs and man the frontlines, do not have the luxury of evolutionary time to make the decisions that confront you daily. The onus is on <u>you</u> to make intelligent and sensitive judgments about intervention, with compassion for the rights and aspirations of the person involved, and with an eye firmly fixed on the hazards inherent in their decisions.

These are difficult questions you must confront, values you must weigh as you deal with abstract legal theories in the concrete reality of the lives of people with whom you work. The task would be somewhat more manageable if legal ambiguity is not compounded by professional ambivalence. My prayer is that we will all encounter fewer clinical professionals who act like bad lawyers and hide behind formal legal rituals and jargon -- like the presumption of competence and the dignity of risk -- to avoid confronting the untidy reality of human problems.

The people with disabilities we all care about need guides and helpers who are concerned enough to be assertive enough to protect them from the catastrophic consequences of their own uninformed or inexperienced judgment. We have all heard a great deal about "safety nets" to protect the poor, the weak and the vulnerable. The safeguards that theoretically exist in community living won't work if each of us values our professional relationships with other agencies more than our commitment to the people they serve.

They won't work if we let a misguided sense of politeness permit on-going harm to vulnerable people.

They won't work if, in order to get along we go along with practices that expose people to unnecessary risk.

They won't work if we turn a blind eye and a deaf ear to the unspoken cries for help.

<u>There is no safety net that can bear the weight of human indifference.</u> And I have yet to encounter a safety net of laws, rules, regulations and policies that was any stronger or more effective than a single concerned and engaged professional, standing shoulder to shoulder with a person navigating the daily challenges of life in the community. Fortunately, there are thousands of such professionals drawn to this field whose personal values and commitment make the idea of consumer freedom more than mere rhetoric, and who make the idea of reinventing quality more than just a dream.

Almost 2,500 years ago, one of the most ancient of our professions was launched with these four words as its enduring foundation: "First, do no harm." That is still good advice for any professional, and to which I would add "and let no harm be done."

INNOVATIVE PRACTICES

Statewide Information and Evaluation Systems

QUEST SURVEY AND CERTIFICATION PROCESS

A unified licensing and evaluation process

Area Served: Massachusetts

Contact: June Rowe, Director of Survey and Certification
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Phone (617) 727-5608 EXT 236/Fax (617) 727-9868

The Massachusetts Department of Mental Retardation (DMR) has integrated its licensing, quality assurance and human rights divisions to form the Office of Quality Enhancement (OQE). OQE has implemented a new provider certification system, replacing previous licensing and program evaluation instruments with the Quality Enhancement Survey Tool (QUEST).

The QUEST is comprised of six quality of life areas: rights and dignity; individual control; community membership; relationships; personal growth and accomplishments; and personal well being. In addition, the QUEST contains a seventh area that defines outcome measures for the organization. Each area within the QUEST addresses outcomes, measures, source, ratings, and comments.

In January 1994, certification based on the QUEST began for all providers. The survey process examines the quality of life of a sample of individuals with disabilities served by providers. Teams of DMR Quality Enhancement Specialists, consumers, and family members conduct the surveys. Each team member conducts individual surveys and cumulative information from the individual reviews is the basis for certifying agencies. During feedback meetings teams present providers with ratings, recommendations, and areas needing improvement. Within 15 days of the feedback meetings, written reports are completed and sent to providers and DMR Regional and Area Directors. The products of the surveys are levels of certification ranging from noncertification to full two-year certification for providers.

QUEST is applicable to both residential and day services, including supported employment and semi-independent living situations. It was developed by persons with various affiliations and pilot-tested with twelve service providers. The Department of Mental Retardation has found QUEST to be not only effective in evaluating the quality of life of people with developmental disabilities, but also efficient in combining several functions into one process.

For more information contact June Rowe at (617) 727-5608, Ext. 236.

RESIDENT OUTCOME LICENSURE SURVEYS

An outcome-based state licensing survey

Area Served: Ohio

Contact: Charles Grunkemeyer, Chief
Office of Licensure
Ohio Department of Mental Retardation and
Developmental Disabilities
Columbus, OH 43266

Phone (614) 466-6670/Fax (614) 644-6676

The Ohio Department of Mental Retardation and Developmental Disabilities' (DMRDD) Office of Licensure uses a survey process placing emphasis on observations and interviews. They call the process the Resident Outcome Licensure Surveys. These surveys have established a friendlier relationship between DMRDD and service providers through a process that focuses on consumer outcomes.

Resident Outcome Licensure Surveys are unannounced and usually occur at times when consumers are home. Beyond monitoring for licensure rule compliance, visits may take place to investigate unusual incidents or complaints. Surveyors use several methods are to assess compliance with the Rules of Licensure. They include: observations of the facilities; interaction between residents and staff; conversations with residents and staff; and record reviews. Surveyors focus on the following areas within the Rules of Licensure: staff training; conditions of the facilities; food and nutrition; clothing and personal effects; fire and safety requirements; drugs and medical procedures; and residents' finances, rights, and individual plans.

At the end of each visit, surveyors document a summary that highlights topics discussed, comments, and suggestions. Surveys conclude with exit interviews, during which the surveyors, staff, and residents have the opportunity to discuss and respond to specific concerns. If warranted, surveyors document citations, and issue them upon exiting.

For more information, or a copy of the Office of Licensure Handbook on Resident Outcome Licensure Surveys, contact Charles Grunkemeyer, Chief, at (614) 466-6670.

QUALITY ASSURANCE IN COLORADO

An outcome and assistive based method for state quality assurance

Area Served: Colorado

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Quality Assurance in Colorado's Division for Developmental Disabilities is moving from rule compliance enforcement to working with providers. While the state will not relinquish its obligation to enforce compliance, it is now sharing that responsibility with providers. The state also is developing a partnership with providers in assuring quality.

Colorado's State Central Office established the Quality Assurance Section in 1985, at which time Colorado had a system of group homes and segregated adult day programs. Colorado was just beginning to develop HCBS waiver, supported employment, family support, and non-congregate residential programs. The system now consists of highly individualized services, including supported living. These changes, in addition to the endorsement by Colorado's governor of outcome-based measures and total quality management, prompted a reassessment of regulatory compliance and service quality evaluations.

The staff of the Program Quality Section (PQS) looked at the relevance of the activities they were performing. They assessed the effectiveness those activities had on helping providers to improve the quality of their services, or assisting consumers to affect the quality of their own lives. They reviewed the work done in other states and talked with national experts in quality assurance and developmental disabilities.

PQS now examines each individual service entity and reviews factors such as: length of operation; results of the last regulatory survey; and size, location, and organizational sophistication. With this information PQS negotiates how they will work with providers to assure quality. Rather than state staff conducting traditional surveys, they talk with providers about how they can work together to review compliance and quality enhancement issues.

For more information or materials contact Heidi Cunningham, Program Manager, at (303) 762-4581.

COLORADO PROGRESS ASSESSMENT REVIEW (COPAR)

Longitudinal evaluation of quality

Area Served: Colorado

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Colorado's Division for Developmental Disabilities' mission statement has established community inclusion, responsible choice, control, belonging, relationships, competencies, talent, security and self-respect as primary values that should be reflected in services to Colorado's citizens with developmental disabilities. To evaluate actual outcomes for persons receiving support against the values in its mission statement, Colorado developed the Colorado Progress Assessment Review (COPAR), a longitudinal evaluation program. COPAR was begun in 1986 with a legislative mandate that the State Auditor's Office (SAO) perform an independent evaluation of the progress of individuals with developmental disabilities. From this mandate a Steering Committee, made up of various stakeholders, was formed to advise the SAO.

COPAR asks structured and unstructured questions directly to a sample of persons receiving services (or proxy respondents when necessary), persons waiting for services, and providers of services on a longitudinal basis to determine program and service outcomes and differences across programs and regions. Questions are also asked pre and post participation in new service initiatives to determine if they have resulted in improvement in the lives of persons served.

Colorado contracts with a private research organization to collect data in the field as well as to gather and evaluate instruments being used elsewhere to address similar issues. These are used to improve their current list of questions in COPAR. Additionally, studies are being conducted that compare the decision-making, satisfaction, and community inclusion of persons with and without developmental disabilities in the Colorado general population to serve as standards of comparison for persons served by the division.

COPAR is managed by the Colorado Division for Developmental Disabilities with funds from state general appropriations ($29,000) and the Division for Developmental Disabilities (approximately $21,000).

Reports from COPAR and various COPAR forms are available by contacting Judy Ruth, Section Chief, at (303) 762-4578.

QUALITY ASSURANCE AND INFORMATION SYSTEMS

A computerized statewide management information system

Area Served: Minnesota

Contact: James Franczyk, Research, Evaluation and Planning Director
Division for Persons with Developmental Disabilities
Minnesota Department of Human Services
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St. Paul, MN 55155

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Developing, maintaining and improving service quality for persons with developmental disabilities requires a variety of technical support, including ready access to information necessary for individual and system planning and review. The quality of information available often determines the quality of decisions made.

Minnesota has developed, and continues to enhance, a fully computerized statewide management information system. Its purpose is to gather, analyze, and report data in response to generic and idiosyncratic needs. The Division for Persons with Developmental Disabilities'(DPDD) management system draws on other databases within and outside the Department of Human Services (DHS), as well its own, to provide information. Examples of data available include: individual information such as service recipient characteristics; services and costs and systemic information, such as county by county cumulative data on service systems; waiting lists; expenditures; and summary client profiles.

DPDD staff and county agencies use both recurring reports and interactive access to obtain information for planning individual programs. Same-service cost comparisons across different geographic regions of the state and different service providers, for example, become possible with collection, storage and retrieval capacity of relevant data in place. Joint planning to focus limited specialized training, technical assistance, and direct service resources become feasible. Policy makers can assess, modify, and enrich policy initiatives based on anecdotal evidence or theoretical positions by using objective analysis of systemwide data.

Ongoing review and expansion of existing databases seeks to assure continued relevancy of the DHS/DPDD management information system. For more information contact Jim Franczyk, Research, Evaluation and Planning Director at (612) 296-2171.

DEVELOPMENTAL DISABILITIES QUALITY ASSURANCE RESEARCH PROJECT

A Longitudinal Assessment of Consumer Outcomes

Area Served: Oklahoma

Contact: Ed Arquitt, Principal Investigator
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Tapping the important dimensions of quality of life and outcomes that are important for and valued by people with developmental disabilities is an important quality enhancement activity.

The Department of Human Services Developmental Disabilities Services Division contracts with Oklahoma State University's Department of Sociology to conduct annual independent assessments of consumer outcomes. Changes in independence, integration, productivity, and satisfaction are tracked longitudinally to measure quality of life enhancement. Assessments ar completed annually on approximately 3700 individuals at a variety of residential sites throughout Oklahoma. Residential types include state school, intermediate care facilities for persons with mental retardation, nursing homes, private homes, group homes, and foster homes, as well as supported, semi-independent and independent living arrangements. The assessment instrument used has three parts: an interview with the primary care-giver, a consumer satisfaction interview, and a qualitative site assessment.

Yearly reports of the survey research are made to the Oklahoma Quality Assurance Advisory Council. Represented on the council are primary consumers, family members, service providers, Department of Human Services staff, Oklahoma Developmental Disabilities Council, research staff and consultants. Survey reports are disseminated to provider agencies who may use the results to improve service quality.

Research staff have accrued considerable experience in the development of a computerized tracking system to follow previously institutionalized individuals as they relocate to community settings. An unanticipated outcome of the study has been the adaptation of the consumer satisfaction portion of the study to a picture book format that allows non-verbal consumers to participate.

Barbara Murray and Amanda Fullerton direct day-to-day activities of the study. They or Ed Arquitt, Principle Investigator, may be contacted at (405) 744-6104.

COMPASS

A quality assurance pilot project based on consumerism, outcomes, management planning and agency self-survey

Area Served: New York State

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Quality Assurance
State of New York Office of Mental Retardation
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Many states are seeking to directly involve consumers, their families, and service providers in quality assurance activities for persons with mental retardation and related conditions.

New York has developed a pilot program involving twenty-four service provider agencies to study the effects of such an approach. Project COMPASS (Consumers, Outcomes, Management Planning, and Agency Self-Survey) will enable these agencies to demonstrate their commitment and ability to provide services of high quality without customary state monitoring and regulatory intervention. The pilot project will design and evaluate an approach combining program operations and regulatory activities and will look to relate consumerism, outcomes, management planning and agency self-survey.

Project goals include: 1) increasing involvement of consumers and their families in the development, monitoring and improvement of services; 2) measuring service quality in terms of desired outcomes defining the quality of consumers' lives; 3) enabling service providers to assume direct responsibility for planning, providing and enhancing services of good quality; 4) encouraging service providers to identify and resolve, through agency self-surveys, unmet needs and service deficiencies; and 5) emphasize a state agency role of assistance and support, rather than regulation and sanctions.

New York will establish Regional Project Advisory Boards composed of service providers and consumers to advise the project participants on appropriate models to test each element of COMPASS and to evaluate the results of the pilot. The goal of the pilot is to identify the best methods to enable COMPASS to be established as an alternative to the traditional survey and certification processes.

COMPASS staff is available to share information and can be contacted at (518) 474-3625.

STANDARDS REVIEW PROCESS OF COMMUNITY LIVING

A quality assurance process and related tools

Area Served: South Carolina

Contact: Susan Thompson, Director
Quality Assurance
South Carolina Department of Disabilities & Special Needs
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Columbia, SC 29240

Phone (803) 737-6533/Fax (803) 743-3593

South Carolina uses a Consultation Model in its quality assurance process for its Standards Review Process of Community Living. In South Carolina this means surveying providers of services to people with disabilities annually on both hard and soft issues, using predetermined standards. When surveyors find problems, they recommend changes. The consultation model allows for constant interaction and exchange of ideas between the providers and the state. Surveyors make quarterly follow up visits to providers for technical assistance.

Small teams of two to three people conduct these surveys, which, unless consumers live in their own homes, are unannounced visits to provider sites. Team members talk to staff and consumers, examine documentation, and observe activities. Administrative surveys are also conducted that look at the managerial components of operating a provider service. Finances, employment practices, and director board records are examples of areas reviewed.

South Carolina revised their review process in 1992 to include outcome-based measures and process measures. Staff reviewers now look at the person first to decide if desired outcomes are present. If outcomes are not present the reviewers determine what processes are preventing outcomes from occurring. Reviewers then make recommendations to the providers on achieving outcomes. Reviewers cite providers immediately for standard noncompliance related to health, safety, rights and accountability. If cited, the provider must make corrective measures without delay.

Providers, parents, and advocates were all involved in the development of outcome-based changes and now are developing a consumer satisfaction survey tool. Susan Thompson, Director, Quality Assurance, attributes this collaboration and the commitment of the State to the design success of the review process. She can be contacted for more information at (803) 737-6533.

UTAH'S OUTCOMES SURVEY

A nonobtrusive quality assessment tool

Area Served: Utah

Contact: Georgia Baddley, Director
Program Quality Assurance
Division of Services for People with Disabilities
Department of Human Services
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The goal of Utah's Quality Assurance Plan is "to motivate providers of services for people with disabilities to achieve and maintain the highest standards through an internal quality assurance plan that places decision making and responsibility at the lowest level and incorporates quality assurance activities into the routine at all levels, including management." The Outcome Based Survey is a vital part of this goal.

One Quality Assurance Team member conducts a nonobtrusive quality assurance assessment using the Outcomes Survey. The survey directs members to observe in the consumers' program settings. Members schedule visits in advance unless there are concerns surrounding a program or individual. Team members use the tool to assess provider services for the consumer based on four standards: personal growth and development; consumer participation in the consumer's Individual Program Plan; consumer participation in Utah life; provider quality assurance plan.

Team members score providers of services on these standards and a report to providers includes recommendations for improvement, and lists areas in which providers excelled. If a provider has not met minimum scores on standards, the provider is expected to develop a Plan of Correction. Technical assistance is available from the Division of Services for People with Disabilities to carry out changes. The Division rewards providers who achieve high scores by reducing surveys. The goal is to induce providers to develop internal quality assurance plans that reflect the values articulated through the Outcomes Survey.

The Utah Quality Assurance Academy developed the Outcome Survey. A variety of stakeholders including parents, advocates, state employees, providers, and consumers compose the Academy. The large group formed the Quality Assurance Advisory Committee to oversee and advise on Utah's Quality Assurance Plan. Outcomes Surveys are conducted separately from licensing and health and safety surveys. Contract compliance is also a separate function, conducted at the region level.

Georgia Baddley, Director, feels having a variety of players involved from the beginning has been integral to the success of this survey tool. She can be contacted at (801) 538-4198 for more information or materials.

SOUTH CAROLINA STATE HEALTH AND HUMAN SERVICES FINANCE COMMISSION

An independent agency that oversees quality assurance for all social services block grant services

Area Served: South Carolina

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In 1984, the state of South Carolina established the South Carolina State Health and Human Services Finance Commission (the commission) to administer Medicaid and federal block grants. The Commission is not responsible for direct service, but instead contracts for services provided under these programs with other government entities, including the South Carolina Department of Special Needs and Developmental Disabilities. A primary responsibility of the Commission is to assure quality of services in these contracts.

With the aid of the Human Services Research Institute and the URSA Institute, the Commission developed a quality assurance system for Social Services block grant services. In developing the quality assurance system five steps were taken 1) understanding the existing system, 2) developing service standards, 3) developing assessment instruments and systems, 4) developing control and enhancement activities, and 5) establishing good communication structures. Goals for quality assurance were also created. They included assuring capability, good practice, productivity, effectiveness, and serving those most in need.

The result is a quality assurance system that is proactive, assistive, and positive. The Commission assists quality assurance efforts of individual state agencies, including the Department of Special Needs and Developmental Disabilities. These state agencies begin their quality assurance procedures by examining critical outcomes. If the critical outcomes are not met, the agency examines critical success variables that have been developed as indicators for the critical outcomes. If this outcome based process does not provide adequate information, the state agency may revert to traditional standards.

In its new procedures the Commission has separated administrative monitoring from person-centered monitoring. Administrative monitoring is now conducted by the Division for Program Monitoring, of the Commission. This allows state agencies to concentrate on person-centered monitoring.

For more information contact Ann Maletic, Department Head, at (803) 253-6154.

Service Agency Development

PERFORMANCE BASED CONTRACTING PROJECT

An outcome-based alternative to ICF-MR quality assurance

Area Served: Minnesota

Contact: Bob Meyer, Assistant Director or Jan Menke, Outcome Based Consultant
Division for Persons with Developmental Disabilities
Minnesota Department of Human Services
444 Lafayette Road
St. Paul, MN 55155

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The state of Minnesota is embarking on an innovative demonstration project, called Performance Based Contracting. Its purpose is to develop and evaluate an effective person-centered demonstration model as the basis of contracting for, and assessing, services sites. The project will compare the demonstration approach with existing process-based approaches to establishing and assuring quality in ICF-MR and other government financed programs for people with developmental disabilities.

Five service provider organizations across Minnesota have been selected as initial demonstration projects. The projects will include approximately 200 people in ICFs/MR and 300 people in other service arrangements. Participating service providers will be working cooperatively with county agencies, advocates, consumers, families, and other members of local communities in developing and implementing projects.

Minnesota's Department of Human Services (DHS) foresees the demonstrations lasting up to four years. They expect the projects will improve providers' ability over time to: offer a wider array of choices to consumers; increase consumer satisfaction with services; achieve and measure desired outcomes; and replace process requirements with performance on things that matter to people. At the end of the demonstration period, the projects may either continue as ICFs/MR or convert to home-and-community-based services.

In these projects, DHS will waive some state rules and regulations. The state is in the process of obtaining needed federal ICF/MR waivers of existing standards. The requested waivers will reduce paperwork and process requirements that do not directly enhance the quality-of-life of service recipients. DHS also expects the waivers to increase program flexibility to achieve desired client outcomes, without jeopardizing health and safety. The Health Care Financing Administration (HCFA) will assist in funding the evaluation, training and technical assistance activities of this project. For more information contact Bob Meyer, Assistant Director, at (612) 297-0307 or Jan Menke, Outcome Based Consultant, (612) 296-1090.

HOMEWARD BOUND CQI

A continuous quality improvement program

Area Served: Minneapolis/Saint Paul

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New Hope, MN 55428

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Homeward Bound, a non-profit provider of residential services to individuals with severe health and physical disabilities, has committed itself to major service reforms focused on providing opportunities for all service recipients to receive the supports they need in homes of their own. In an effort to improve the ongoing program, and support the major organizational change that lie ahead, it is implementing a quality management program based on the philosophies of W. Edwards Deming and other quality management leaders. Homeward Bound refers to its program as Continuous Quality Improvement (CQI).

Homeward Bound's CQI program was initiated by Homeward Bound board member Kristine King of Quality Process Associates. Ms. King brought her quality management experience to Homeward Bound through CQI training sessions. CQI training on the use of statistics, team building, problem solving, and CQI philosophies began with managers and is working its way to all employees. This training is conducted in three hour sessions, over four days, in groups of twenty employees.

An executive steering group sets up teams of employees, giving them clear missions and goals. Teams develop methods of solving problems, designing strategy, and planning for operations based on their missions and goals. Before teams carry out ideas, they pass ideas by the steering group. Each team has a team leader who works exclusively on the team project. Currently Homeward Bound is developing facilitators for teams with a train-the-trainer approach.

Quality management initiatives of this type generally are not fully implemented for three to five years. Homeward Bound, however, already feels that there is evidence of its effects on the agency, including for example, employees seeking increased responsibilities, and vendors such as transportation organizations, increasing their cooperation with Homeward Bound.

For more information on Homeward Bound's CQI program contact Gordon Gandy at (612) 535-6171, or Kristine King at (612) 561-2428.

SERVICE ENHANCEMENT

A volunteer-based service assessment and training program

Area Served: Connecticut

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Service Enhancement Unit
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East Hartford, CT 06108

Phone (203) 725-3935/Fax (203) 566-3680

Enabling people with disabilities to live the life they desire is a focus of the Connecticut Department of Mental Retardation's Service Enhancement Unit (SEU). The SEU accomplishes this goal by supporting provider's efforts in increasing service quality. The SEU is open to any way providers desire help. SEU fosters trust among people through: voluntary participation; open and candid talk; and respectful ways of being with one another.

Some providers use SEU's Values Exploration Workshops. These providers explore what choice, competence, respect, participation, and good relationships mean to create a common understanding of what the service is striving for in supporting people. SEU leads staff through a self-exploration process during twenty hours of training. Such explorations enable participants to hear the many opinions and theories of others. Using an expanded way of thinking, they create an array of values-related information on which to make decisions.

Others use SEU's Service Quality Review Process. These providers freely invite a team of individuals to talk to people receiving services, their friends, families, and staff; and to spend time seeing what life is like for everyone involved. Service Quality Review Processes result in Enhancement Strategy Plans, which are carried out and periodically modified.

The Connecticut Department of Mental Retardation manages and funds Service Enhancement at an annual cost of approximately $120,000. The program evolved from a deinstitutionalization court order and began in 1986. A Guide To Service Quality Review and The Service Quality Review Process are available by contacting Joseph Harrison-Becker or Dennis Mitchell at (203) 725-3935.

OREGON SYSTEM OF CONTINUOUS QUALITY IMPROVEMENT

A statewide approach to quality improvement for agencies

Area Served: Oregon

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Salem, OR 97308-0967

Phone (503) 363-8609/Fax (503) 378-1979

The philosophies of W. Edwards Deming and Total Quality Management, are at the heart of Oregon's System of Continuous Quality Improvement. Oregon's Mental Health & Developmental Disability Services Division has implemented, through a contract with Paradigm Systems, a project that has taken components from corporate America's quality movement and adapted it for the developmental disabilities field.

Paradigm Systems asks Oregon residential and vocational providers to volunteer to gather information about their organization from consumers, families, program staff and their board of directors. They then ask providers to select areas for improvement. Paradigm Systems offers a seven-step process to help providers use survey information internally and develop and carrying out plans for improving and monitoring the quality of their programs. At the end of the year, providers share a short description of their improvement plans with the Oregon Mental Health & Developmental Disability Services Division.

Meredith Brodsky, of Paradigm Systems, says providers who have used the system benefit from an overview of their programs and provider staff gain control over their work environments through Continuous Quality Improvement. She feels this project will also influence the lives of consumers directly, as providers who use this system will concentrate on those improvements that have the greatest impact for their consumers.

Oregon conceived of its System of Continuous Quality Improvement in 1989 within Oregon's Mental Health & Developmental Disability Services Division. It was an outgrowth of the design of quality assurance surveys. Implementation began in 1992. State personnel, consumers, families and providers all helped to design the project. All funding is through the state of Oregon, which oversees the project through the Division. Paradigm Systems currently operates Oregon's CQI system.

Materials are available on Continuous Quality Improvement from Paradigm Systems, including: Manual of Quality Indicators; Handbook of Continuous Quality Improvement; Best Practices in Oregon; Facilitator's Guide; eight sets of surveys; and a brochure. They may be contacted at (503) 363-8609.

PERSON-CENTERED SYSTEM DESIGN PROJECT

A system-wide assessment and planning process

Area Served: Minnesota

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Human Services Research & Development Center
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Saint Paul, MN 55102

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Many criticisms of the "human services system" center on the fact that agencies, systems and services are often not designed around serving the people who are dependent on them, but rather serving the purpose of professionals, regulatory and funding bodies, and the existence of "the system" itself. Many professionals, aware of these weaknesses, would prefer to operate services differently, but lack the structured methods to do so. While one agency that provides services may be able to improve many of its own practices, there is still a limit on what can happen in the lives of individuals who receive services without a system-wide understanding, direction, and plan.

The Human Services Research and Development Center of St. Paul, MN has been awarded a one-year grant from the Emma B. Howe Foundation to support system-wide planning in the Faribault-Martin Counties of Minnesota with possible continuation for a second year. When proposed in 1993, all eleven major providers of services to people with developmental disabilities in the two-county area agreed to participate in this system-wide assessment and planning process.

The project will utilize an agency change model called "Framework for Accomplishment," authored by John and Connie O'Brien. The system-wide analysis will allow the participants to: a) assess the quality of services provided throughout the system by examining the lives of individuals served and determining desirable futures for each of them; b) develop a clear vision for system design based on person-centered values; and c) determine methods and constructive actions to take at the agency and system level, so as to support more desirable, individualized lives and futures for persons who receive services.

HSRDC will continue to work with the participating agencies to implement the constructive actions and methods of the course for one to two years. People involved will include individuals with developmental disabilities, family members, board members, direct care, management, county and state staff, and community members.

This project began late fall of 1994. For further information, contact Angela Novak Amado, Ph.D., Executive Director, (612) 227-3292.

Systemwide Quality Enhancement

CONTINUOUS QUALITY IMPROVEMENT IN NEW HAMPSHIRE

A state agency initiative to empower consumers and direct-care workers

Area Served: New Hampshire

Contact: Margaret Aubin, Program Planning & Review Specialist
Bureau of Developmental Services
Division of MH/DS
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New Hampshire's Bureau of Developmental Services, in adopting the concepts of continuous quality improvement (CQI), seeks to empower consumers with developmental disabilities and their direct care workers.

The Bureau sponsors, through the state's twelve area agencies, dissemination of Dr. W. Edwards Deming's ideas on quality enhancement, emphasizing the importance of building-in quality from the start, rather than depending on later monitoring to find deficiencies. In New Hampshire's application of this approach, quality is defined by the consumer and becomes the responsibility of the consumer's support persons. Support persons are encouraged to identify issues and problems requiring attention, and to expect appropriate assistance in resolution.

Managers across the state attended two-day seminars in continuous quality improvement. These seminars stress values and new perspectives on organizations and attitudes. Seminars are followed by monthly facilitated discussions to deepen participants' understanding of CQI theory and examine, in a collaborative environment, participants efforts to apply CQI. Tools to implement the theory are introduced and utilized.

The Bureau identified three emerging outcomes from New Hampshire's program: 1) continuing high attendance at monthly discussion meetings by provider executives, 2) increasing interagency networking, and 3) occurring movement from traditional quality assurance reviews to collaborative self-assessment.

For more information contact Margaret Aubin, Program Planning and Review Specialist, at (603) 271-5032.

CONSUMER EMPOWERMENT PROJECT

A consumer-focused quality enhancement project

Area Served: New York State

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Division of Quality Assurance
New York State Office of MR/DD
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The goals of New York State's Consumer Empowerment Project are improving communication between consumers and agencies that provide services, and improving the quality of life for consumers. With the funding aid of the New York State Developmental Disabilities Planning Council, the State of New York's Division of Quality Assurance has undertaken this multi-faceted project.

First, the project has redesigned its quarterly publication, *The Quality Assurance Network*, with a consumer focus. Over 5200 people nationwide receive this publication that provides a forum for discussing issues related to providing services to people with developmental disabilities. Second, the project developed the Consumer Opinion Questionnaire (COQ) with the help of hundreds of consumers, parents, providers, and advocates. They designed it as a tool for agencies, advocates and consumers. Its purpose is to include the opinions of consumers in the quality assurance process. COQ is voluntary, can be modified, and can be done anonymously. A video tape is available to accompany the COQ, as is a toll free hot line.

Last, the Consumer Empowerment Project began piloting third party citizen/consumer monitoring in January 1993. The project conducts this unobtrusive evaluation through interviews and observations, and does not look into records and other confidential areas. Called CARE, for Consumer Advocate Review and Evaluation, it seeks to fully include consumers in the survey process. Some consumers cannot read or write, and so, there are no written check lists that surveyors must follow. The absence of check lists help to keep the CARE survey from taking on a regulatory feeling. In addition, the project provides extensive training and apprenticeship periods to promote greater consumer participation. Surveyed agencies receive written reports of CARE findings and recommendations.

For more information or materials, contact Joel Altschul, Assistant Director, at (518) 474-8007.

CERTIFICATION PROJECT: AGENCIES WORKING TOGETHER IN PARTNERSHIP

A program certification process

Area Served: Missouri

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Missouri Department of Mental Health
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In past years, the quality of residential services for persons with developmental disabilities typically has been measured by input and process indicators, rather than by achievement of desired outcome. Continuously seeking to improve the quality of services provided to people with disabilities has become another quality paradigm.

To address these changing perspectives of quality, the Missouri Division of Mental Retardation and Developmental Disabilities (DMRDD) has developed an initiative called Certification Project: Agencies Working Together In Partnership. This project is based on the precept that:

> "to provide quality services and supports requires a partnership between CMRDD and its contracted providers. The individual with developmental disabilities and/or family will determine our effectiveness in meeting their needs and requirements. Individuals being supported and their families should have an ongoing role in monitoring the quality and effectiveness of [the] supports provided."

Missouri's certification project is intended to reorient DMRDD's quality assurance activities to continuous improvement in the performance of agencies in achieving valued outcomes for people with developmental disabilities. The agency's aim is to establish a partnership with service providers so that "services and supports provided are within the context of the individual's preferred lifestyle."

Missouri's certification model is continuous-loop, feedback driven process that consists of an outcome-based survey, the development of an enhancement plan based on survey feedback, technical assistance and training to assist provider agencies, and ongoing reviews of provider agency performance. Biennial, formal certification surveys are complemented by family and consumer reviews of agencies.

For more information contact Kate McClain, Program Coordinator, at (314) 751-8674.

HCBS WAIVER QUALITY ASSURANCE

A quality assurance approach for HCBS

Area Served: Wisconsin

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Medicaid funding of Home and Community Based Services (HCBS) as an alternative to ICF-MR or nursing home care, can enhance states' capacity to provide individually responsive services in integrated community settings. Most states now have one or more Medicaid waivers to provide HCBS.

Wisconsin's Medicaid HCBS waiver program long has been a source of information and technical assistance for individuals and agencies in other states interested in HCBS programs. Modeled after its state-funded Community Option model, Wisconsin's HCBS program has worked toward building in quality through a menu of services approach. This approach focuses on each individual's needs and preferences since its beginning in 1983.

Beyond the effort to address quality issues from the planning stage onward, Wisconsin's state waiver team maintains ongoing oversight of HCBS recipients' care through frequent personal contacts. In the past year, staff of the state waiver team visited more than one-half of all HCBS recipients. They met with families and service providers and talking with each individual receiving HCBS to determine their satisfaction with their current circumstances and services.

Although staff review compliance with basic regulatory standards, during team visits, attention is directed toward individual quality-of-life indicators, such as community participation and integration and opportunities for personal choice. Emphasis in the state oversight process is on identifying and providing needed technical assistance and support to improve service quality, rather than on compliance enforcement. Waiver team activities supplement, but do not supplant, quality assurance efforts by case managers and others at the local level.

Further information is available by contacting Dennis Harkins, Director, or Ken Golden, Program Manager, at (608) 266-1520.

STANDARDS FOR PROVIDERS OF SERVICES

A set of state standards combined into one chapter of rules

Area Served: Iowa

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Division of MH, MR, & DD
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Streamlining state rules and regulations for service providers allows them to spend less time deciphering regulations and more time concentrating on consumers. The State of Iowa has combined its various provider standards into one standards chapter. This chapter includes a section of core standards that is central to all programs. Also included are separate sections outlining those standards that are unique to individual programs. The new standards also have service definitions that are consistent across programs.

Provider standards did include separate requirements for governance, administration, and services provision areas and separate service definitions for each program. This caused duplication of definitions and standards to which providers must follow. The state anticipates the new standards will offer clarification to providers and less duplication of administrative duties for the state. Consolidated monitoring is another advantage of the new standards. Under old standards, Iowa surveyed individual programs within provider organizations, resulting in several surveys for many providers. Under the new standards, the state will coordinate the survey to occur only once every three years. New rules also include a process for systematic self-assessment of the achievements of provider goals and objectives. The rules will require the use of a program evaluation report to establish future program goals and objectives.

The Bureau of Quality Assurance and Support has suspended accreditation activity for three months to provide statewide training on the new rules. The new standards went into effect December 1, 1993. For a copy of the new chapter 24 or for other information on Iowa's quality assurance program contact Ruth Schanke, Bureau Chief, at (515) 281-6221.

NEW YORK STATE COMMISSION ON QUALITY OF CARE FOR THE MENTALLY DISABLED

An independent commission to administer protection and advocacy services and influence quality

Area Served: New York

Contact: Clarence J. Sundram, J.D., Chairman
New York Commission on Quality of Care
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Since 1978, New York State has had an independent Commission on Quality of Care for the Mentally Disabled (the Commision). The Commission is broader in scope and influence than most state Protection and Advocacy services (P & As). Its state statute has enabled it to exercise broad oversight within the mental hygiene system and serve as an advocate for people with disabilities. The Commission has a seat in the Governor's Cabinet, allowing it substantial influence on policy making. The Commission, as an independent overseer, also investigates all unusual deaths, abuses, and complaints; is an independent source of advice for state policy makers; conducts policy analysis and cost effectiveness studies and fiscal investigations; and distributes findings through published reports and its widely distributed newsletter.

The Commission goes beyond its investigations by making positive changes in the delivery system. For example, the Commission's Surrogate Decision Making Committee Program hastens the process of getting medical services to those who cannot make decisions independently.

The Commission also publishes a series of case studies entitled *Could This Happen In Your Program?* Available to any facility or interested party, the studies present brief analyses of cases investigated by the Commission. The investigative findings, corrective actions and lessons learned are intended to serve as inservice training tools and to engage facility staff in discussions of their policies and practices as they endeavor to answer "Could this happen here?"

Clarence Sundram, Chairman, sees the Commission as influencing the quality of community services in three ways. First, the Commission increases access for people with mental disabilities to community health care. Second, it has promotes desegregation for people with disabilities in communities. Last, the Commission conducts studies of community residential programs to help connect quality of life issues with state policies.

For more information contact Clarence Sundram, J.D., Chairman, at (518) 473-4057.

OHIO SUPPORTED LIVING QUALITY ASSURANCE

A nontraditional systematic approach to quality assurance

Area Served: Ohio

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Ohio has developed a quality assurance approach for supported living that is nonintrusive, outcome-based, and attends to the goals that people hold for themselves, not the characteristics and processes of programs or residential settings.

In 1989 the Ohio Legislature created Supported Living programs in Ohio and required the Department of Mental Retardation and Developmental Disabilities (the Department), and County Boards of Mental Retardation/Developmental Disabilities to monitor the quality of supported living services. The state mandated the Department to "ensure that services are furnished in a manner that provides for the individual's health, safety, and welfare." In addition, a quality assurance rule was added that focuses on people served. It seeks to determine how well persons' needs are met, whether choice is supported, and if persons' quality-of-life are enhanced. It outlines for County Boards eight areas to promote.

The Department monitors the county boards for compliance in areas such as individual service plans, policies, and procedures. The Department also conducts selected quality assurance reviews with county boards using a Consumer Inventory. Counties may adopt this instrument for their quality assurance reviews but may use their own instruments if they measure the eight areas defined in the Quality Assurance rule.

The Ohio Association of County Boards of Mental Retardation/Developmental Disabilities, the Ohio Private Residential Association, advocacy organizations and the Department of MR/DD developed the quality assurance program for supported living. For more information contact Bethanne Cliffe, Chief, at (614) 644-5972.

STRATEGIC PLAN FOR REVITALIZATION OF MENTAL RETARDATION SERVICES IN PHILADELPHIA

A citywide systematic plan to enhance quality

Area Served: Philadelphia, PA

Contact: Michael Covone, Acting Director
Mental Retardation Services
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Philadelphia, PA 19107

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Efforts to assure and enhance service quality for persons with developmental disabilities may benefit from a systematic planning process involving all interested parties. Philadelphia, Pennsylvania is advancing such an effort.

Representatives of consumers and their families, advocates, service providers, and the governments of Philadelphia and Pennsylvania conceived of the Community Collaboration. They formed, in Philadelphia, to plan a restructuring of services to meet the needs of all persons with mental retardation in the city. The product of this effort was a recently published strategic plan identifying intended beneficiaries and specifying forty-two outcomes for the next several years.

Based upon the most valued aspects of people's lives, the plan is shaped by a commitment to using best practices to support these values in the lives of persons with mental retardation. The plan documents how each intended outcome will support one or more identified values.

Philadelphia's Collaboration groups outcomes into one of three clusters. Responsible parties assure the achievement of outcomes and a planning track manager is responsible for implementation of each cluster. The Philadelphia Office of Mental Health/Mental Retardation and the Pennsylvania Office of Mental Retardation share general responsibility for implementation of the plan. A Planning Advisory Committee, appointed by the Director, Philadelphia Office of MH/MR will monitor progress and assist plan compliance.

Further information, including more details concerning the planning process, values and outcomes identified, and strategy for implementation, may be obtained by writing to or phoning Michael Covone, Acting Director, at (215) 592-5489.

WYOMING QUALITY REVIEW PROJECT

A person-centered approach to systematic change

Area Served: Wyoming

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Cheyenne, WY 82001

Phone (307) 632-3496/Fax (307) 638-0815

The Wyoming Protection and Advocacy (P&A) System is sponsoring a project to enhance the quality of community services throughout Wyoming. The state P&A has contracted Patterson and Associates to perform the project. Patterson and Associates use their "Quality Review Process," which is based on the philosophy that management of quality services cannot depend on the measurement of deficiencies alone, but must have access to measures of achievement as well.

Two stages of the project are near completion: 1) a statewide assessment of each of Wyoming's nine regional service providers which produced written reports for providers and the P&A agency of each provider's indicators of quality and barriers to improvement; and 2) three volunteer provider agencies engaging in a personal futures planning process with each of two consumers served by each provider agency. In addition each of the three provider agencies conducted forums of consumers and family members to discuss the meaning of quality of life. From these activities direct care staff planned how to support consumers in achieving their desired personal outcomes. Provider agency management, planned how management could best support its staff in such efforts.

Terry Cooper, Executive Director of ARK Regional Services, one of the three volunteer agencies, hopes that Wyoming will incorporate the personal futures planning technique of goal development into the State's Individualized Plannign Process. She is pleased with the change the Quality Review Project has brought to her agency and may be contacted for more information at (307) 742-6641.

For more information from the Wyoming P&A project contact Jeanne Thobro at (307) 632-3496. Joseph Patterson, Patterson and Associates, may be contacted at (602) 743-9552.

Values Infusion

IT'S ABOUT LIFESTYLE CHOICES

Training focused on consumer choice

Area Served: Delaware

Contact: Hope Ellsworth, Training Administrator
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Georgetown, DE 19947

Phone (302) 934-8031, Ext. 346/Fax (302) 934-6193

Traditional human service systems develop programs and put people into them. A new way of providing services is being considered across the country that suggests the system should start with individuals and build services around them. All people need to be provided settings where their important lifestyle choices can be met. "It's About Lifestyle Choices" is a training program that promotes such choice.

"It's About Lifestyle Choices" is conducted for providers, professionals, direct-care workers, and parent advocacy groups. It takes a light hearted look at the system today and examines specific changes that each person participating in training could make. The focus is on one-on-one grassroots change. Choice is a key value articulated through the training, as participants look at ways to detect consumers' desires. Training is conducted in one-day workshops that overview the following topics:

- new directions in service delivery effecting the person,
- new directions in service delivery effecting the system,
- how the system has made people fit into the system,
- moving beyond readiness,
- choices,
- labeling-"the label trap",
- personal commitments for change.

The training was developed by the former Delaware Community Living Coalition with the help of Michael Smull, University of Baltimore. The Delaware Community Living Coalition has merged with the Delaware Advocacy Coalition.

It's About Lifestyle Choices receives no special funding. Volunteers conduct the training and their employers allow volunteers to conduct training during workshop hours. Employers also donate supports such as copying services. For more information, contact Hope Ellsworth, It's About Lifestyle Choices trainer, at (302) 934-8031.

ALASKA SERVICE PRINCIPLES

A set of statewide service principles

Area Served: Alaska

Contact: Mike Renfro, Program Administrator
Developmental Disabilities
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Alaska has several programs to assure quality in community services for people with developmental disabilities, all based on Alaska's nine service principles.

These nine principles range from "services are the result of on-going planning" to "services are culturally appropriate." Information from state staff, the public, parents, and service providers have aided in several refinements of the principles. Each year the revised principles are presented to approximately 800 parents at a state conference, and distributed to service providers, parents, and planning councils.

Consumers entering the service system complete an evaluation questionnaire related to the Service Principles before services begin. If the consumer is not satisfied, funding is not released and the state looks into what can be done to satisfy the consumer. This tying of funding to the Service Principles allows the state to ensure quality of services from the onset. A non-state agency conducts a similar evaluation with people who have been in the service system one year.

Mike Renfro, Program Administrator, feels it is hard to separate the Service Principles from the entire service delivery system. He says the Service Principles are the foundation for everything else in the system. He stresses that having funding attached to the consumer is essential in assuring quality. Service providers know that consumers can easily move to another provider if services quality is low.

For a copy of the booklet Service Principles or the video tape Individualized Services or general information contact Mr. Renfro, Program Administrator, at (907) 465-3370.

Consumer & Citizen Monitoring

QUALITY MEASUREMENT INSTRUMENT REVIEW

A summary of quality assurance measurement instruments

Area Served: United States

Contact: Bill Allen & John Shea
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As part of its effort to develop the Colorado Program Assessment and Review (COPAR) the Division of Developmental Disabilities, of the Colorado Department of Institutions, contracted with Allen, Shea, and Associates (ASA), in cooperation with Claudia Bolton Forrest and Nicholas DeCilla, to examine the state-of-the-art and best practices throughout the country.

ASA reviewed seventy-two measurement instruments in quality assurance measurement. They looked at how these tools compared to the values stated in the Division's missions statement, including: friendship & belonging, self-esteem, competencies & talents, decision making, community inclusion, and satisfaction.

ASA's survey began in spring of 1992 with a survey of directors of State ARCs, State MR/DD directors, and Colorado agencies providing advocacy or other services. In addition they conducted a general literature search to identify quality assurance instruments. Throughout their search they used a snowball technique, asking informants for leads to creators and users of instruments, and to literature in which results were presented.

Among the conclusions of ASA were that most tools: have been developed as a method of evaluating services or reviewing compliance with standards; and are concerned with lifestyle, environments, and behavioral characteristics. They also determined that most have not: considered alternative methods of data collection for persons who have limited communication skills, been studied to determine reliability or validity, been standardized, focused solely on quality-of-life, and offered interpretive guidelines. ASA additionally found that some instruments included an interview with the person with a disability and some quality-of-life measures.

The review is available as part of the Measurement Tool Survey's *Final Report* from Allen, Shea & Associates for $9.95. For more information call Bill Allen or John Shea at (707) 258-1326.

QUALITY ASSURANCE FOR PEOPLE MOVING

A quality assurance module for deinstitutionalism

Area Served: Washington State

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In Washington over six hundred people with developmental disabilities have moved from large institutional settings to community residential programs. In response, the state has developed a quality assurance module to be used by volunteers to examine health and safety, power and choice, status, integration, relationships, and autonomy of persons who have moved from institutions to the community.

A team consisting of a quality assurance manager and two volunteers ask people who have moved questions about their homes, work, friends, and activities. They also survey case managers, families, and residential and vocational program staff. The goal is to assess the person's move, find out if consumers like where they live, and determine if consumers have the community support they need. A report is then completed and action plans developed to correct any problems. Aggregate trends are analyzed and used to assess state processes for transitioning people.

In 1989 the Division of Developmental Disabilities appointed an evaluation core group to comprehensively review all services provided by the division. From this core group a task force on quality assurance for people moving from large institutions to the community, was developed. The task force used the Rainier Follow-Along Project as a springboard for developing a protocol for ensuring that people moving were receiving individualized, community supports.

The Division of Developmental Disabilities first implemented Quality Assurance for People Moving in January 1990. It is managed and funded by the Division of Developmental Disabilities at a cost of approximately $450,000 per year. Volunteers are reimbursed for expenses but are not paid for their services. The Division is now seeking to expand this quality assurance program to additional service areas.

Maureen Weeks, Program Manager, can be contacted for information on Quality Assurance for Moving People at (206) 586-6180. Information on the Rainier Follow-Along Project is available from Bruce Treichler, Developmental Disabilities Planning Council, at (206) 753-3375.

OKLAHOMA ADVOCATES INVOLVED IN MONITORING (OK AIM)

A consumer monitoring system

Area Served: Oklahoma

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As more persons with developmental disabilities return from institutions to their communities, often living in small, dispersed residences, an effective process to assure the quality of their community based services is required.

An Oklahoma court order to deinstitutionalize persons with developmental disabilities referenced a monitoring process that would increase the involvement of consumers and their families. After reviewing various systems for monitoring service quality, a statewide committee of consumers and staff selected the Oregon model. The Oklahoma Department of Human Services contracted with the Tulsa Arc to establish and operate a monitoring program, Oklahoma Advocates in Monitoring (OK AIM).

Under the leadership of John Gajda and a statewide committee of consumers, teams of OK AIM volunteers composed of consumers, family members, friends and advocates for persons with disabilities seek to assure and enhance service quality. Teams visit provider agencies to evaluate services and suggest improvements, they also gather and report information to assist consumers in choosing among services and providers. Evaluations by OK AIM indicate that providers are responsive to surveyor team suggestions and that direct care staff often display more positive attitudes toward persons with disabilities as a result of OK AIM initiatives.

The OK AIM program has developed a handbook containing a total of 26 items in 4 categories to be used by surveyors in reviewing services to persons with disabilities. The handbook is employed both in the six hours of training provided to all surveyors and as an ongoing resource in conducting reviews.

To obtain further information and materials about OK AIM contact Dennis Bean at (405) 521-6265 or John Gajda at (918) 582-8272

TEAM ADVOCACY PROJECT

A quality-of-life monitoring program

Area Served: South Carolina

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Suite 208
Columbia, SC 29204

Phone (803) 782-0639/Fax (803) 790-1946

The South Carolina Protection and Advocacy System (SCP&A) uses an innovative monitoring system that looks beyond health, safety, and regulatory compliance, called the Team Advocacy Project. SCP&A still focuses upon these concerns, however they also look at quality-of-life issues.

The Team Advocacy Project trains volunteers to conduct surprise inspections of facilities using a survey instrument designed to assess the quality of resident living conditions. They are trained to look at consumer needs, environmental conditions, health, safety, service coordination, and quality of life. Volunteers may look at Plans of Care. This is especially helpful in evaluating service coordination. The team members also survey the basic living conditions of the residence. For instance, they look for humanizing touches such as pictures on the walls. They look to see if residents have places to keep personal belongings and ask themselves, "Would I like to live here?"

After the team of three visits the residence, using their observations and interview, the Team Advocacy Project Coordinator prepares a report. She then sends it to the Joint Legislative Governor's Committee on Mental Health and Mental Retardation, and state agencies. The committee asks the residence owner to respond within thirty days, and a re-inspection of the residence is scheduled to see if improvements have been made.

The project is managed by the central office of the SCP&A. It is overseen by an advisory committee with members from various associations and SCP&A. The Team Advocacy Project is funded by State legislative committee and line item money.

For materials or information on the Team Advocacy Project contact Linda Blank, Coordinator, at (803) 782-0639.

CARE REVIEW COMMITTEES

A volunteer-based monitoring program

Area Served: Iowa

Contact: Carl M. McPherson, State Long-Term Care Ombudsman
Kris Bullington, State Care Review Committee Coordinator
Iowa Department of Elder Affairs
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Des Moines, Iowa 50309-2801

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To help assure the quality of community services in Iowa, committees of volunteer community persons are assigned to every long-term care community facility, and make periodic unannounced facility visits. Regardless of funding source, ownership, or demographic consumer makeup, each long-term care facility licensed in Iowa must have a Care Review Committee to conduct monitoring, offer suggestions for improvement, and help resolve problems.

The Care Review Committees were designed to reflect the community, and thus volunteers from all areas of the community are solicited by the Department of Elder Affairs. Each facility must have a committee of at least three members, and the goal is a one volunteer to fifteen residents ratio per facility. Currently there are over 4000 such volunteers in Iowa.

Volunteers review residents about their quality of life satisfaction at least once a year and meet quarterly to review their findings and discuss problems. Reports from these meetings are given to facility administrators along with yearly reports volunteers produce about each resident. The Care Review Committees have no formal authority, and so rely on their relationships with the service provider administrator for resolution of problems. Minutes of their quarterly meetings and reports on the problems addressed are provided to the Area Agencies on Aging.

Carl McPherson, Long-Term Care Ombudsman, administers the Care Review Committee program through the Department of Elder Affairs. He would like to see the volunteers take on roles as change agents for their facilities and move more toward advocacy for the residents. He feels this could be accomplished by adding local ombudsmen to train and guide volunteers, and handle complaints at the local level.

For more information, contact Carl McPherson or Kris Bullington, at (515) 281-5426.

EASTERN SHORES COMMUNITY MONITORING

A volunteer-based quality enhancement program

Area Served: Maryland's Eastern Shore

Contact: Susan Atwood, Director
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Salisbury, MD 21801

Phone (410) 219-2828/Fax (410) 219-2838

Eastern Shore Community Monitoring (Community Monitoring) enhances the lives of Maryland Eastern Shore citizens with developmental disabilities. Community Monitoring is a volunteer organization that offers multifaceted services in cooperation with the Eastern Shore Regional Developmental Disabilities Administration and eighteen independent nonprofit agencies. A group of parents started Community Monitoring in 1987.

Family members, provider staff, consumers, professionals, advocates, and community members are among the one-hundred trained volunteers who donate their time to Community Monitoring. Volunteers actively work throughout the nine Eastern Shore of Maryland counties to develop positive relationships with agencies, direct care workers, families, and consumers.

Community Monitoring encourages positive lifestyles through Residential Monitoring, Companion Connection, Family Networking, and Lifetime Planning. Residential Monitoring volunteers visit state-licensed homes to promote quality lifestyles. Companion Connection establishes friendships between people with challenges and members of the community, sororities, fraternities, and churches. Family Network provides one-on-one confidential volunteer support to families of people with developmental disabilities. The booklet, *Personal History for Lifetime Planning*, allows families and consumers to record personal information and future aspirations.

All services offered by Community Monitoring are supplements to licensing, intra-agency requirements, accreditation and other services. Agencies are not legally bound to participate in Community Monitoring conducted surveys and activities, however, all area agencies avail themselves of the beneficial services. Volunteers do not have access to confidential records, procedure compliance reports, or performance standards reviewed by other agencies.

A grant from the State of Maryland provides $25,000 in annual funding. This money pays for overhead, travel, and one half-time director. Volunteers may request reimbursement for expenses but seldom do. For more information or materials contact Susan Atwood, Director, at (410) 219-2828.

QUALITY REVIEW TEAMS

A quality-of-life monitoring program

Area Served: Nebraska

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Lincoln, NE 68509

Phone (402) 471-2851/Fax (402) 479-5145

The Nebraska Developmental Disabilities Division manages a pilot project that uses consumers and other volunteers to conduct nontraditional quality of life reviews with a person-centered, desired outcomes approach. In June 1991 the Nebraska Legislature passed the Developmental Disabilities Act that included significant changes for people with developmental disabilities. Among these changes was the requirement for the establishment of quality review teams (QRT) in each of Nebraska's six geographic developmental disabilities regions.

The statute specified that each team should consist of four appointed members. Each team must include at least one consumer and one person who is neither a consumer nor a relative of a consumer. No person on these teams may be an employee of a government or provider agency. Nebraska Developmental Disabilities Division reimburses QRT members for necessary expenses incurred in performing QRT duties. Each team will conduct annual quality of life surveys for people with developmental disabilities, investigate complaints, and make recommendations related to residents' quality of life.

The State Developmental Disabilities Division has contracted with the Arc of Nebraska to carry out a pilot project of the Quality Review Teams in two of its six regions. These pilot projects began in September 1992 and have continued in Fiscal Year 1994. The Nebraska Developmental Disabilities Planning Council funded approximately $40,000 for the pilot project. Initially the pilot project will focus on the people living in group homes and agency operated residential settings.

For more information contact Cathy Anderson at (402) 471-2851.

Community Relationship Building

NEIGHBORHOOD SUPPORT PROJECT

A project that supports the inclusion and contributions of people with disabilities in the life of their neighborhoods

Area Served: Seattle

Contact: Mary Romer/Carolyn Carlson
Residential Technical Assistance Project
Catholic Community Services
1932 1st Avenue, #905
Seattle, WA 98101

Phone (206) 443-9592/ Fax (206) 728-2318

The Neighborhood Support Project is a community building effort that focuses on bringing people with disabilities together with people and places in their neighborhood to support the inclusion and contributions of all people into neighborhood life. The project assumes that the presence and participation of people with disabilities is a community responsibility, not just a family or systems' responsibility. Many of the strategies employed and thinking behind the project have been strongly influenced through consultation with Kathy Bartholomew-Lorimer and John McKnight's work in the Logan Square neighborhood of Chicago.

Staff of the project work in partnership with the Fremont Neighborhood Council. This neighborhood association in Seattle is committed to discovering the capacity of the neighborhood to welcome and include people who are isolated and disenfranchised. The general focus of the work of this partnership is to learn together what it might take to seek out, welcome and offer support to all members of the neighborhood. On behalf of the Fremont Neighborhood Council, staff spend time getting to know people with disabilities and their families living in the neighborhood. Once a sense of people's gifts, capacities and interests is attained, members of the Neighborhood Council are enlisted as *introducers* to people, associations and places in the local community where common interests might be shared. Staff then act as *guides* to support the person's initial participation with ordinary citizens in typical neighborhood activities, events and associations. It is the intent that staff will shift ongoing support needed by individuals with disabilities to community members.

In this next year of the project, the principal management has been shifted from staff of the Neighborhood Support Project to the Fremont Neighborhood Council. The Council has been awarded a grant from the City of Seattle's Department of Neighborhoods to develop a "Time Dollar" project. The project, called Fremont Time, will be a service exchange venture where everyone's time will be valued and exchanged equally. Catholic Community Services will subcontract with the Fremont Neighborhood Council so that the Council can directly hire someone to support the participation and contributions of people with disabilities in this effort. The Neighborhood Support Project staff will participate on the steering committee and act as consultants to Fremont Time.

For more information contact Mary Romer or Carolyn Carlson at (206) 443-9592.

COMMUNITY CONNECTIONS

A program that connects people to their communities

Area Served: Idaho - Region 6

Contact: Frances Roberts, Program Manager
Developmental Disabilities Program
Idaho Department of Health and Welfare
Region 6
421 Memorial Drive
Pocatello, ID 83201

Phone (208) 236-6000/Fax (208) 236-6328

The more people involved in a person's life, the greater the number of people who are available to monitor the quality of services. Community Connections facilitates this aspect of quality assurance. Its goal is to include people with disabilities into local communities through natural connections.

Modeled after Associated Integration's Education for Community Initiative this program facilitates relationships between people with developmental disabilities and people in communities. Community Connections accomplishes this by examining the interests of people with disabilities and then seeking community members with similar interests. The program supports these connections by providing staff who make introductions, and gives financial support by providing fees for dues and/or transportation.

The inclusion of well-connected community members on Community Connection's committees has been essential in matching people with disabilities to appropriate groups. Consumers, program staff, and staff from other agencies also make up the committee.

In addition to making community connections, this program educates community groups about the value of inclusion of people with disabilities into communities and trains other agencies. A resource guide of community groups featuring a topical index is also a Community Connections' project.

For more information contact Frances Roberts, Program Manager, at (208) 236-6000.

COMMUNITY ADVOCATE PROGRAM

A program matching volunteers with people with disabilities toward community integration

Area Served: Hennepin County, Minnesota

Contact: Jerry Mellum, Individual Advocate
Arc of Hennepin County
Diamond Hill Center, Suite 140
4301 Highway 7
Minneapolis, MN 55416

Phone (612) 920-0855/TTY (612) 920-4392/Fax (612) 920-1480

Many people with developmental disabilities living in institutional or community settings lack contacts and supports outside of the service-delivery system. The Community Advocate Program matches volunteers one-on-one with individuals with developmental disabilities who are transitioning into the community. These volunteers lend personal support and resources.

Hennepin County Community Services and Arc of Hennepin County continue to collaborate on this successful effort. This cooperation allows for expanded support resources for volunteers including mileage reimbursement, training, continuing education credits, and related emotional and social support.

Volunteers spend several hours, two or three times monthly, with their matches; their relationships, however, may last a lifetime. Each relationship is unique, forged by individual circumstances, personalities, and needs. The volunteer serves variously as companion, individual advocate, link to the community, negotiator, and advisor. Community Advocates assist the individual with a developmental disability in learning social and independent living skills as they explore the new community with their volunteer. The goals of this partnership are advocacy, community inclusion, protection, and the strengthening of community.

For more information, contact Jerry Mellum, Individual Advocate, Arc of Hennepin County, at (612) 920-0855 or Judy Corrao, Volunteer Manager, Hennepin County Community Services, Volunteer Services, at (612) 348-7481.

Technical Assistance

OUTCOME BASED PERFORMANCE MEASURES

A guide to measuring service outcomes

Area Served: United States

Contact: James Gardner, Chief Executive Officer
Accreditation Council on Services for People with Disabilities
8100 Professional Place, Suite 204
Landover, MD 20785-2225

Phone (301) 459-3191/Fax (301) 577-0703

Outcome Based Performance Measures were developed by the Accreditation Council on Services for Persons with Disabilities (the Council) to shift the definition and assessment of quality in services from provider inputs and processes, to measurements of consumer outcomes. This change in focus reflects the belief that the consumer's satisfaction and quality of life are the best indicators of the quality of services that person is receiving.

The *Outcome Based Performance Measures* instrument is designed to be administered on an individual consumer basis. Its 30 items examine such areas as personal goals, choice, relationships, dignity and respect, health, security, satisfaction, environment and social inclusion. The items were selected using individual and focus group interviews to identify priority outcomes that people with disabilities indicated to be most important to them. The Council field tested the Outcome Based Performance Measures for validity and reliability and continues to conduct validity and reliability tests as part of its national accreditation program quality reviews. Outcome Based Performance Measures is used to engage in activities responsive to the individual consumer; to conduct self-assessment by service provider agencies of their organization's effectiveness in supporting consumers in achieving their desired outcomes; and to conduct independent quality reviews of service provider agencies.

The Council has completed accreditation reviews with several organizations across the United States using the new *Outcome Based Performance Measures*. The review process is resulting in "recommendations that are more specific and practical." The Council plans to test new ways to involve people with disabilities, parents, staff, and community members in the review process.

To purchase a copy of *Outcome Based Performance Measures* or to request additional information, phone the Council at (301) 459-3191.

TECHNICAL ASSISTANCE/LEADERSHIP FOR QUALITY

A framework to move from state to local quality assurance

Area Served: Pennsylvania

Contact: Nancy Thaler, Director
Bureau of Community Programs
Office of Mental Retardation
Pennsylvania Department of Public Welfare
Harrisburg, PA 17105-2675

Phone (717) 787-3700/Fax (717) 787-6583

Many states are making efforts to evolve from systems of centralized, compliance-oriented quality assurance to decentralized local systems. Pennsylvania has undertaken a multifaceted approach to achieving this goal.

The Pennsylvania Office of Mental Retardation's Planning Advisory Committee composed of stakeholder representatives has published, *Everyday Lives*. This document outlines an action framework for improving services for persons with mental retardation and related conditions. A statewide Positive Approaches Subcommittee of professionals, government representatives, and consumers knowledgeable about and committed to quality enhancement has led to formation of seven regional committees. Each committee has its own program for enhancing quality. For example, Lehigh County Citizens Outreach volunteers visit provider homes, serving as active listeners and personal contacts for residents; and Luzerne County Community Services Monitoring Project brings consumers and family members together to review problems and service needs, has access to the county administrator, assesses services, and suggests positive changes.

Pennsylvania has assigned three state facilitators to provide state technical assistance in quality enhancement to twelve counties. Quality enhancement training is available statewide through the Office of Mental Retardation. State licensing regulations have been revised to be more flexible and less burdensome, and to delegate responsibility from the state to the community level. Emphasis has been on increased involvement of consumers and their families in monitoring and shaping services and developing policy.

Pennsylvania's effort to move toward a consumer-centered, community based quality enhancement program clearly is multifaceted and still in evolution. It may be of particular interest to states in similar circumstances. For more information contact Nancy Thaler, Director, at (717) 787-3700.

LIFE QUILTERS PROJECT

A project supporting people with challenging behaviors

Area Served: West Virginia

Contact: Don Kincaid, Project Coordinator
University Affiliated Center for Developmental Disabilities
West Virginia University
Research & Office Park, 955 Hartman Run Road
Morgantown, WV 26505

Phone (304) 293-4692/Fax (304) 293-7294

The Life Quilters Project seeks to improve the lives of West Virginians with mental retardation and challenging behavior who are at risk of losing their community placements or who are in transition from institution to community living. Operating from a person-centered values base and a broad ecological perspective, the project works to enhance the capacity of service providers to create and maintain supports of high quality for this population.

Life Quilters affects services to persons with developmental disabilities at a number of levels. Organizations are helped to formulate policies and define practices, identify and obtain resources, plan and provide services, design and conduct staff training, and monitor and improve quality. Families, service providers, and interested others are taught person-centered techniques to deal with challenging behavior. Individual consumers are assisted to develop new abilities, establish satisfying relationships, and gain personal dignity and respect.

The program follows a four phase sequence in conducting projects, similar to phases used in many continuous quality improvement programs: 1) plan; 2) learn; 3) do; and 4) evaluate. Critical activities within each project include developing memorandums of agreement, developing personal profiles and future plans, assessing service delivery, conducting individual functional analyses, developing work plans, identifying a work group, and evaluating outcomes. Life Quilters offer long term consultation, short term consultation and positive behavior support training to agencies and individuals. The full commitment of the focus consumer, the consumer's family and the consumer's support services providers is considered essential to success.

Annual costs of West Virginia's Life Quilter program are near $250,000. For further information and materials concerning the project, contact Don Kincaid at (304) 293-4692.

DEVELOPMENTAL DISABILITIES TRAINING INSTITUTE

A training, technical assistance, and research center

Area Served: United States

Contact: George S. Baroff, Director
Developmental Disabilities Training Institute
CB# 3370, Hill Commercial Building
University of North Carolina at Chapel Hill
Chapel Hill, NC 27599

Phone (919) 966-5463/Fax (919) 962-2659

The principle of normalization, as articulated by Dr. Wolfensberger, is at the heart of training and research conducted by the Developmental Disabilities Training Institute (DDTI) at the University of North Carolina-Chapel Hill. For DDTI this means looking at what consumers need, not what the system can provide. DDTI focuses on community integration and service quality.

This organization does both consumer and provider staff training, along with consultation and training for provider management. Staff training includes topics such as sexuality, gentle teaching, person-centered planning, staff and consumer relationships, employment, community activities, and consumer instruction. A special 80-hour curriculum was developed for the training of residential direct-care staff.

Advocacy training for consumers and families is available through DDTI. Consumers and families participate in all operations at DDTI, from facilitating to designing training. DDTI additionally does research related to service provision at the state and national levels. Recently, DDTI did a nation wide study on best practices in integrative employment services for persons with developmental disabilities.

In 1963, North Carolina's General Assembly set up the Training Institute to train and provide technical assistance for staff of programs serving persons with mental retardation. The DDTI operates under the University of North Carolina at Chapel Hill, and is associated with, but not a part of, North Carolina's University Affiliated Program (UAP). State and federal grants, contracts, private foundation grants, and fees fund the program.

More information and materials, such as research reports, training materials, articles and books written by DDTI staff are available by contacting Nancy Dotson, Research Associate, at (919) 966-5463.

Personnel Training and Professional Development

UNIVERSAL ENHANCEMENT

A staff training program on inclusion

Area Served: National

Contact: Thomas Pomeranz, Chief Clinical Officer
VOCA Corporation
5555 Parkcenter Circle, Suite 200
Dublin, OH 43017

Phone (800) 837-8622, Ext 3273/Fax (614) 793-8584

VOCA Corporation, a service provider for people with developmental disabilities, uses an innovative training program called Universal Enhancement. The training teaches service provider staff the skills of inclusion and relationship building. Universal Enhancement promotes opportunities for individuals to experience social interactions of value and meaning. It opens inclusionary pathways that historically have been limited by attitudes, regulations, and funding mechanisms.

Through Universal Enhancement, training staff learn to: listen, extend options for choice, role model, and design a prosthetic environment. Using a "circle of friends" approach, trainers ask trainees to complete a *Quality of Life Profile* on themselves. This approach assesses the relationship between valued activities in one's life and the extent to which these activities involve others. Trainers ask participants to think of a person with a disability and the number of people in that person's life. These people should not be relatives, paid staff, or people with disabilities. Participants then identify the activities valued in the person with disability's life. These exercises help trainees recognize the barriers to inclusion many environments build.

Universal Enhancement provides staff with the tools to overcome constraints and limitations that prevent inclusion in highly regulated environments. These tools are uncomplicated and unconstrained. For example, staff may encourage individuals with disabilities to give and do for others.

VOCA's Universal Enhancement program has resulted in an increase in the quality-of-life for the people they serve and an increase in the quality-of-working conditions for their staff. People with disabilities are now engaging in more choice and decision making. Trained staff, for example, have been involved in interviewing potential VOCA personnel. VOCA staff now operate under the assumption of doing with people, versus doing to people. In turn, people served by VOCA are immersing in reciprocal giving. Many people served volunteer for community service or offer assistance to neighbors and co-workers.

For more information, and complimentary newsletter articles on Universal Enhancement, call Thomas Pomeranz, Chief Clinical Officer, at 1-800-837-8622, Ext 3273.

NORTH DAKOTA STATEWIDE DEVELOPMENTAL DISABILITIES STAFF TRAINING PROGRAM

A statewide training program for direct service staff

Area Served: North Dakota

Contact: Demetrios Vassiliou/Mary Mercer
North Dakota Center for Disabilities
Minot State University
Minot, ND 58707

Phone (701) 857-3047

In order to assure and enhance community service quality for persons with developmental disabilities, direct service staff training is essential.

Since 1983, North Dakota has provided such training through a cooperative effort of the Department of Human Services (DHS), Minot State University (MSU), and long term care provider agencies throughout the state. North Dakota requires full-time direct service staff to demonstrate knowledge and skills in topic areas addressed in sixteen training modules. Service providers employ state certified regional trainers to teach these modules. Full time staff must complete eight modules in each of the first two years of employment. Providers are encouraged to require the same of part-time staff. MSU faculty also offers workshops throughout the state specific to interests of direct care staff.

The training program offers a six-step professional development sequence including: entry level orientation; position-based competency training; a training module Certificate of Completion; an Associate of Arts in Developmental Disabilities; and a Bachelor of Arts in Mental Retardation. Learning options include formal instruction, on-site demonstration, mentoring, and self-study with or without discussion group participation. Staff may test out of individual modules by demonstration of required competencies.

DHS supports the program by funding service providers and MSU's University Affiliated Program's materials development and training activities. State funding to MSU for this project in Fiscal Year 1994 is $68,290.

Key program elements include: cooperation among state DHS, MSU, and service providers; comprehensive, but flexible, training materials; a statewide system of individual training records; state standards for direct service staff training; a career training sequence leading to academic degrees; and program consistency through time and across North Dakota.

Information and materials are available from Demetrious Vassiliou, Director of Field Training Programs or Mary Mercer, Field Training Coordinator, at (701) 857-3047.

KANSANS EDUCATING AND EMPOWERING PERSONS WITH DEVELOPMENTAL DISABILITIES

A statewide training program for direct service staff

Area Served: Kansas

Contact: Kathleen Olson, Community Training Coordinator
University Affiliated Program at Parsons
University of Kansas
2601 Gabriel, Box 738
Parsons, KS 67357

Phone (316) 421-6550, Ext. 1859/Fax (316) 421-6550, Ext. 1702

The skills and attitudes of direct service staff are significant factors in the quality of services provided and the quality of life experienced by service recipients. An accessible and affordable ongoing staff training program becomes particularly important when relatively low staff salaries make it difficult to hire experienced and well-trained personnel.

Kansas University Affiliated Program, with support of the Kansas Department of Social and Rehabilitation Services (SRS), has developed a statewide training program for direct service staff. It is called Kansans Educating and Empowering Persons with Developmental Disabilities. This program trains staff to address such quality issues as personal health, functional assessment of behavior, skill development, personal choice, personal planning, community presence, and meaningful social relationships. The Kansas program uses a train-the-trainer model, and has a series of six instructional modules presented over fifteen training sessions with optional college credits available.

Process measures of the program's effectiveness to date are positive. Training direct care staff in advance of training their supervisors resulted in some early difficulties. Another beginning challenge was inequity in training opportunities among all areas of the state. In the future, training of both direct service staff and their supervisors together as teams will be recommended.

Success of the program thus far is attributed to the development by the project of highly detailed training modules with involvement and support of all key stakeholders. More information about the program and the set of training modules may be obtained by contacting Kathleen Olson, Program Coordinator, at (316) 421-6550, Extension 1859.

PROGRAM STATUS REVIEW

An internal review for service provider staff

Area Served: Bentonville, Arkansas

Contact: Keith Vire, Executive Director
NW Arkansas Family Support Services
P.O. Box 697
Bentonville, Arkansas 72712

Phone (800) 748-9768/Fax (501) 271-0819

In 1988 group of family with the mission of keeping their children with disabilities at home incorporated themselves into Northwest Arkansas Family Support Services (NAFSS). Today it continues to support families and individuals in their homes and communities with such services as supported living and supported employment. This agency is worth examining not only for its uniqueness, but also for its innovative and successful internal staff quality review process called the Program Status Review (PSR).

This internal review process is designed and implemented by employees. In a supported living situation, for example, all staff for a supported living home come together to formulate standards, guidelines, and training needs. These standards and guidelines reach beyond state minimum standards and reflect the goal of improving services. Staff then use these guidelines to check their own performance. Additionally, cross checks are conducted by staff of different NAFSS residential sites. From these checks weekly status reports are issued in clear and easy to understand terms.

The purpose of PSR is not to reprimand employees who do not meet standards but to open discussion on what can be done to achieve standards that staff have established for themselves. PSR has taken on a friendly competitive mode among employees that reflects the agency's overall competitive attitude to offer the best services.

PSR began in January 1992 to address problems from the rapid growth of NASS, and is viewed by many as having contributed to improved services, increased employee morale, and lower employee turnover. For more information contact Keith Vire, Executive Director, at (501) 273-0338.

LEISURE IS FOR EVERYONE (Life Training)

A training program for recreation service providers

Area Served: Georgia

Contact: Lynn K. Poole
c/o Governor's Council on Developmental Disabilities
2 Peachtree Street, NW
Third Floor, Suite 210
Atlanta, GA 30303

Phone (404) 667-3007/Fax (404) 657-2132

The Georgia Governor's Council on Developmental Disabilities has developed a program, Georgia LIFE (Leisure Is For Everyone) Training, to train recreation professionals to include persons with developmental disabilities in existing recreation programs and activities.

Modeled after that of the University of North Carolina, the program adds information on the Americans with Disabilities Act. Training videos and other materials produced by the program assist those trained by program staff to train others upon return to their own localities. Cited as key elements in the program's success are the support of the Georgia Parks and Recreation Association and the Governor's Council on Developmental Disabilities, availability of continuing education credits for trainees, a strong public relations effort, and the inclusion of persons with disabilities as members of the training staff.

The Governor's Council on Developmental Disabilities provides funding of $25,000 to Georgia LIFE Training. The program is managed through a contract with the consulting firm, Power Plus, Inc., headed by Ms. Lynn Poole. Ms. Poole expects to use Paralympic athletes and speakers involved in tennis, theater, water, and music programs in upcoming LIFE Training Workshops.

To inquire about videos and other training materials phone the Georgia Governor's Council on Developmental Disabilities at (404) 657-2126. For other information about the Georgia LIFE Training program phone Lynn Poole at (404) 667-3007.

STORY WRITING

A staff story writing program

Area Served: Madison, Wisconsin

Contact: Gail Jacob, Executive Director
Options in Community Living
22 North Second Street
Madison, WI 53704

Phone (608) 249-1585/Fax (608) 249-3372

Connecting people to the meaning of their work enhances the quality of services at Options in Community Living where staff commitment is built through the practice of story writing. Staff members then share their stories at monthly staff meetings.

Story writers use their narratives to explore their thoughts and feelings about issues of importance to them related to their work at Options in Community Living. The stories are structured much like journal entries or personal letters. They provide glimpses of on going relationships and careers, and offer a chance to see which experiences are significant to staff.

Options in Community Living staff have found Story Writing to be a helpful way to find meaning in their daily work, make sense of difficult situations, and raise hard questions. Story Writing also helps strengthen staff relationships with their organization and one another. These stories communicate the challenges, frustrations, dilemmas, and rewards in serving people with developmental disabilities.

Staff members feel more connected and able to release stress as a result of these Story Writing experiences. Gail Jacob, Executive Director, says the quality of staff work at Options in Community Living has increased due to this unique program. She also attributes a new sense of organizational intimacy to Story Writing. Essential to the success of Story Writing has been the requirement that all staff participate each month. Some staff members are nervous at first, but most come to enjoy writing and sharing their stories. Ms. Jacob feels others embarking on similar programs should separate their programs from other staff requirements.

Remembering the Soul of Our Work, a book of stories by Options in Community Living staff, and other information and materials are available through Ms. Jacob by calling (608) 249-1585.

PEER REVIEW FOR QUALIFIED MENTAL RETARDATION PROFESSIONALS

A QMRP training and internal review process

Area Served: Louisiana

Contact: Sue Merrill, Program Manager
Division of MR/DD
1201 Capitol Access Road
P.O. Box 3117
Baton Rouge, Louisiana 70821-3117

Phone (504) 342-0095/Fax (504) 342-1384

People with developmental disabilities living in the community need competent people to assist them with needed supports. The State of Louisiana Peer Review for Qualified Mental Retardation Professionals (QMRPs) is a strategy to provide a person centered training, evaluation, and quality assurance tool for staff to obtain such competency.

Through a clear definition of responsibilities and outcomes, the Peer Review guidelines provide a basis for QMRPs about how to do their jobs more effectively. Agencies use Peer Review guidelines to evaluate the strengths and weaknesses of QMRP performance. They are flexible enough to be used in any situation. They do list, however, some necessary elements that are present in any setting for the QMRPs to adequately perform their jobs. The guidelines are a training and internal review instrument, and not designed to be another survey.

The accompanying Peer Review process takes place face-to-face by peer review teams. These teams consist of an out of state person, a facility QMRP, and a QMRP from another facility. Resulting from the Peer Review process is the development of action plans and technical assistance for the evaluated QMRPs. The goal of the Peer Review Process is to develop a system that can: produce a common understanding of the roles and responsibilities of QMRPs; focus on outcomes and not punishment; upgrade residential facilities; and improve service entities.

Peer Review began in February of 1991. The Division of Mental Retardation/Developmental Disabilities administers and funds the project at approximately $75,000 annually. The Peer Review for QMRPs Best Practices Guidelines, packets and other information are available by calling Sue Merrill, Program Manager, (504) 342-0095.

INTEGRATED TRAINING

An early child care training program

Area Served: North Dakota

Contact: Helen Danielson, Director
North Dakota Early Childhood Training Center
North Dakota State
P.O. Box 5057
Fargo, ND 58105

Phone (701) 237-8289/Fax (701) 237-7174

North Dakota's Integrated Training program is enhancing the quality of care for young children with disabilities. This module based training program helps child care providers become more comfortable with children with special needs and educate childcare providers on inclusion. The intended outcome of this program is to increase the number of childcare providers for children with disabilities.

Integrated Training's modules are based on Child Development Associate (CDA) credentials. Professionals conduct module workshops using an interactive style to get workshop attenders involved in the module topic. For example, module seven on creativity may have attenders creating machines in which people play the parts of the machine. Later they are asked to adapt this activity for children with disabilities.

North Dakota child care staff are not required to attend modules. Training, however, is free and continuing education units at North Dakota State University are available which may be applied toward a CDA. Since the program's beginning in April 1992, attendance at training modules has steadily increased. Historically, Integrated Training was available only in urban areas, leaving many North Dakotans unreachable for training. This year, however, Integrated Training is reaching remote rural areas.

Integrated Training resulted from a shortage of child care providers for children with disabilities. The Americans with Disabilities Act, along with growing awareness of the absence of a systematic training approach, were also influential in its development. Funding is provided for Integrated Training by the North Dakota Developmental Disabilities Council and North Dakota Human Services.

For copies of the training modules or more information contact Helen Danielson, Director, at (701) 237-7174.

NORTH DAKOTA PROJECT TO IMPROVE SERVICES TO OLDER PERSONS WITH DEVELOPMENTAL DISABILITIES

A training initiative for people who work with older persons with developmental disabilities

Area Served: North Dakota

Contact: Demetrios Vassiliou/Mary Mercer
North Dakota Center for Disabilities
Minot State University
Minot, ND 58707

Phone 1-800-233-1737

North Dakota Center for Disabilities (NDCD) at Minot State University offers a multi-faceted program of both pre-service and inservice training to North Dakotans who provide services to older persons with developmental disabilities.

Collaborative training efforts between Aging Services and NDCD provides training for Title III Aging Service Provider staff and Senior Companions in one-day workshops on "Aging and Developmental Disabilities" during the first grant year. Regional workshops planned for the second grant year will focus on joint training with staff from community providers of services to persons with developmental disabilities and aging services staff. Workshops will focus on delivering services to people with disabilities, both life-long and age-related, in integrated settings and how providers can network to create successful integration opportunities.

A stipend for a three semester undergraduate course in "Aging and Developmental Disabilities" is offered to both professionals and paraprofessionals in the Developmental Disabilities System and Aging Services. Participants may take the course through self-study modules or through class or workshop attendance. Coursework for students preparing for human service careers and pursuing gerontology minors has been enhanced to promote better understanding of aging consumers with disabilities. A graduate course on Interdisciplinary Studies through interactive video has been developed. It is designed to introduce an ecological systems approach to the study of aging persons with developmental disabilities.

A national conference "Aging and Developmental Disabilities: A Vision for the Future" was held in May, 1994. Participants from many states took part in the 3 day conference which included presentations from national experts in the field. Participants from Departments of Aging, Developmental Disabilities, Protection and Advocacy and Minot State University, learned together how to better meet the needs of individuals who have developmental disabilities and who are aging. The national conference will be an annual activity of the training project.

Information and materials are available from Demetrios Vassiliou, Director of Field Training Programs, or Mary Mercer, Field Training Coordinator, at 1-800-233-1737.

Advocacy Training
and
Support for Individuals
and
Families

FAMILY SUPPORT NETWORK

An information, referral, advocacy, and network service

Area Served: Greater Fall River Area, Massachusetts

Contact: Jeanne Vincent, Network Coordinator
Adsum, Inc.
105 Bank Street, PO Box 1511
Fall River, MA 02722

Phone (508) 678-6550/Fax (508) 677-9239

Education and information are important ways to enhance quality in services. Family Support Network works to strengthen education and information available to families of children with developmental disabilities in southeastern Massachusetts. Family Support Network provides referral to, and information on, a variety of resources of potential assistance to families on both a local and statewide basis. Family Support Network also provides educational advocacy, family assessment, a resource library, and works through its network to create needed services for families for whom services are currently unavailable.

The idea for Family Support Network came from people with developmental disabilities who receive supported living services from Adsum Inc., a private nonprofit organization. These adult consumers of services suggested that a referral and information service might help keep children out of institutions. Adsum responded by applying for and receiving a grant from the Massachusetts Department of Mental Retardation in 1988. This grant offers funding that allows Family Support Network to provide services to families without charging fees.

Over two-hundred families have used the services of Family Support Network. Many of these families have shown gratification with services by volunteering for projects and referring other families to Family Support Network. An evaluation survey of families has shown them pleased with the partnership concept that supports parents in taking on leadership roles in their children's lives. Many families, however, did express a desire for connection to recreational activities for their children, which Family Support Network is actively addressing.

Family Support Network is managed by Adsum and operated by Adsum staff and volunteers. For more information on Family Support Network, contact Jeanne Vincent, Network Coordinator, at (508) 678-6550.

MOBILIZING FAMILIES

A training and information project for families

Area Served: Jefferson County, CO

Contact: Jo Lynn Osborne, Assistant Executive Director
Association for Community Living in the Foothills
710 Kipling, Suite 100
Lakewood, CO 80215

Phone (303) 232-1338/Fax (303) 232-9370

Quality services for people with disabilities require consumer information and communication. When providers better inform consumers, consumers are given the opportunity to better articulate their desires and influence service quality. Unfortunately, families with children who have disabilities often do not receive adequate information, nor are involved in meaningful dialogues about services for their children.

The Mobilizing Families Project attempts to address these problems by providing information enables families to access resources, make changes when needed, plan for the future, and impact the service system. A basic belief of this project is that families will make the best choice for themselves if they have complete information. In order to promote decision making, the project presents as much information as possible to families in an eight-week training period. Families start by looking at their own issues and evaluating what their community looks like. They then move on to resources in the community. Throughout the training, the project gives families information on resources and the service system.

The project offers some assistance to training attendees, but does not pay presenters. For example, Mobilizing Families provides for attendees respite service expenses, free training, and free training materials. Over 100 parents have attended Mobilizing Families training. ACL in the Foothills trained forty-seven parents during the first two years of the project. Now the Jefferson County Infant Toddler Interagency Resource Council is conducting training for parents.

Jo Lynn Osborne of the ACL in the Foothills may be contacted for more information at (303) 232-1338. For materials, contact Mary Erickson of the Developmental Disabilities Council at (303) 894-2345.

PARTNERSHIP FUND

A program that funds advocates and consumers to participate in events

Area Served: Georgia

Contact: Harry Burkett, Community Relations Coordinator
Governor's Council on Developmental Disabilities
Third Floor, Suite 210
2 Peach Tree Street NE
Atlanta, GA 30303

Phone (404) 657-2126/Fax (404) 657-2132

Encouraging the inclusion of people with developmental disabilities, and advocates in a wide range of events concerning developmental disabilities is the goal of the Partnership Fund. An expected outcome of this funding is the general empowerment of consumers and families and their involvement in planning and policy making. The ultimate goal is that their inclusion will enhance the quality of services.

Georgia's Governor's Council on Developmental Disabilities makes funds available to organizations so they can include advocates and consumers with developmental disabilities in the planning stages of events concerning developmental disabilities. These events include forums, workshops, conferences, training events, task forces and other policy making processes. The Council also considers funding for consumer inclusion in other innovative projects.

People who previously could not afford to attend the activities are now able to participate because the council reimburses attendees for travel and other travel expenses. Some organizations sponsoring events have covered costs to the individuals and families, as or before they occur, and the organization is later reimbursed from the Partnership Fund.

The Partnership Fund began in May of 1992. The Governor's Council on Developmental Disabilities funds and organizations sponsoring events provide financial support for the Partnership Fund. For more information or to receive *The Partnership Fund Packet*, contact Harry Burkett, Community Relations Coordinator, Governor's Council on Developmental Disabilities, at (404) 894-2028.

PARENT CASE MANAGEMENT AND PARENT CASE MANAGEMENT FOR PEOPLE OF COLOR

An empowerment and training program

Area Served: Minnesota

Contact: Marijo McBride, Coordinator
Parent Case Management Program
Institute on Community Integration
University of Minnesota
150 Pillsbury Drive S.E., 103 Pattee Hall
Minneapolis, MN 55455

Phone (612) 624-6830/Fax (612) 624-9344

The goal of the Parent Case Management Program is to reach persons with disabilities, parents, and guardians to participate more fully in the management of services. Parent Case Management promotes empowerment through training and technical assistance. Key in training is knowledge of rules, systems, and resources.

This program began in 1986 by training parents, and moved on in 1992 to train facilitators to bring the ideas of Parent Case Management to communities. The program provides support for both parents and facilitators who are now out in their communities conducting training and technical assistance. Facilitator training includes a one-day session covering state-of-art philosophy in case management issues for persons with developmental disabilities, plus resources and skills to implement the Parent Case Management Program. Training surrounds implementation the program on both a one-to-one and group presentation basis. Parent Case Management facilitators receive a resource guide, facilitator's guide, handouts, and a newsletter subscription. Parent Case Management also provides facilitators technical assistance for implementing the program, and a $100.00 stipend.

Parent Case Management for People of Color is a program within Parent Case Management. Similar to Parent Case Management, it is committed to creating flexible family support that builds on the unique capacities of families. Through collaboration with leaders in the African-American and Native American communities and community organizations, the program seeks to be an effective and culturally sensitive tool for empowerment of individuals with disabilities and their families.

Marijo McBride, Project Coordinator, Parent Case Management Program, says consumers are demonstrating their empowerment in the use of the service system a year and beyond after Parent Case Management training. She attributes the success of the program to support of key players through technical assistance, networking, training, and the availability of a stipend.

Parent Case Management has been funded through the Minnesota Governor's Planning Council on Developmental Disabilities and the Institute on Community Integration, which also manages and supports the program. The Parent Case Management for People of Color is funded in part by the National Institute on Disability and Rehabilitation Research. It is an adaptation of the Minnesota Arc Suburban Parent Case Management program, and The Orange County California Regions Services Center's Parent Coordinator Program.

Contact Marijo McBride, Coordinator, at (612) 624-6830 for more information or materials.

PARTNERS IN POLICYMAKING

An empowerment and training program

Area Served: Minnesota

Contact: Colleen Wieck, Executive Director
Minnesota Governor's Planning Council on Developmental Disabilities
300 Centennial Office Building
658 Cedar Street
St. Paul, MN 55155

Phone (612) 296-4018/Fax (612)297-7200

To achieve true quality assurance, consumers of services and supports, and their families, need knowledge, skills, and opportunities to effectively express their needs and concerns. Partners in Policymaking was developed in Minnesota in 1987 by the Governor's Planning Council on Developmental Disabilities (DD Council) as a way to develop new leadership, provide intensive training, and build a shared vision throughout the state. Over two-hundred individuals are graduates of Minnesota's Partners in Policymaking program, and Partners in Policymaking has been replicated in twenty-five states.

Partners in Policymaking trains consumers and their families about state-of-the-art practices and services, and gives them the knowledge and skills needed for influencing policy makers. Graduates of this training become actively involved in promoting quality through advocacy for themselves and their families, and through participation in public activities. These advocacy efforts focus on such areas as personal choice, personal planning, community presence, employment, supported living, education, family support, and technology.

Since 1991, Minnesota Partners in Policymaking graduates have been involved in a longitudinal study. Quantitative data collected showed that over ninety percent of Partners in Policymaking graduates were able to secure better services as a result of their participation in this community leadership program. A majority of graduates used skills acquired through the Partners in Policymaking experience to influence public officials. A majority also were serving on a committee or commission, and had the opportunity to educate the public about the rights and needs of persons with disabilities.

Qualitative data showed that graduates rate Partners in Policymaking as an excellent, worthwhile, and invaluable training program. Graduates additionally rated their ability to secure appropriate services as good or excellent. Partners in Policymaking gives consumers and their families the knowledge, skills, and insight to recognize when and where change is necessary; the tools to clearly and factually present information to policymakers; and the confidence to effectively advocate for positive systems change.

There is a variety of information available about Partners in Policymaking, including a manual, recruitment brochures, and curriculum materials. Minnesota DD Council staff urge people to call them about the program directly at (612) 296-4018.

COMMUNITY RESOURCE TEAMS

A rural model for the empowerment of communities

Area Served: Alaska

Contact: Robin Ynacay-Nye, Director
Supported Family Living Services
Hope Cottages, Inc.
540 West International Airport Road
Anchorage, AK 99518

Phone (907) 561-5335 ext. 421/Fax (907) 564-7429

The formulation of Community Resource Teams (CRTs), defined by the community, meaningfully involves consumers, parents, and advocates in designing, implementing, and quality assuring chosen supports. These teams act as community hubs to produce community owned supports responsive to unique rural needs.

CRTs grew out of a group of parents, from the rural town of Dillingham, desires to get services in their community. Formerly, those with disabilities had go to metropolitan areas to receive services.

Concerned people such as parents, teachers and Alaskan Native leaders now compose CRTs. These teams act as advisory councils to Hope Cottages, Inc., a nonprofit private provider of services to people with developmental disabilities. They also solicit local support, act as connections to their communities and advocates, address problems, and provide for networking and informal education about the service system. CRTs have been instrumental in accessing state funding for respite care, case management, and family support, along with funding to buy a small group home.

Robin Ynacay-Nye, Director, Supported Family Living Services for Hope Cottages, says it is important for those working with such teams to remember that team members must be taken seriously and need tangible, results-oriented projects in order to stay focused. She may be contacted for more information at (907) 561-5335, ext. 421.

PUEBLO DEVELOPMENTAL DISABILITIES/MENTAL HEALTH CONSORTIUM

A consortium that seeks to prevent incarceration or institutionalization of people

Area Served: Colorado

Contact: Larry Velasco, Executive Director
Pueblo County Board for Developmental Disabilities, Inc.
115 West Second
Pueblo, CO 81003

Phone (719) 546-0572/Fax (719) 546-0577

In the absence of an inclusive, integrated system of planning and services, persons with dual diagnosis of mental retardation and mental illness are often denied appropriate and necessary services to fully realize their potential. The same is true of many individuals with mental retardation who are criminal offenders.

In 1987 the Pueblo County Board for Developmental Disabilities, in partnership with a number of other community agencies, and with funding from the University Affiliated Program at Colorado University, began the Pueblo Developmental Disabilities/Mental Health Consortium. The Consortium is a voluntary organization, without special funding, made up of community leaders in human services, the justice system, vocational rehabilitation, and other agencies. Consortium members seek to prevent the incarceration or institutionalization of persons with developmental disabilities, and either mental illness or involvement in the criminal justice system. Consortium members provide these people opportunities to live in the community with necessary supervision, treatment and supports.

Hiring a consultant; arranging a visit to Pueblo by staff from a Pennsylvania project similar to the Consortium; and supporting Consortium members' attendance at professional meetings are a few examples of the project's ongoing efforts to benefit from the experiences and expertise of others. In addition to planning and implementing services for persons within the target population, the Consortium has served to direct and coordinate special resources across traditional programmatic barriers to the benefit of individuals who require more than a single program may offer. Critical steps in developing this program were defined as 1) developing a thorough knowledge of the community; 2) identifying and enlisting key community leaders; 3) nurturing respect and trust among Consortium members. A training manual has been developed by the Developmental Disabilities/ Mental Health Consortium and is available at minimal cost. For the manual or further information contact Larry Velasco, Executive Director, at (719) 546-0572.

NEIGHBORHOOD LIVING PROJECT

A research, training, and demonstration project

Area Served: Oregon

Contact: Steve Newton, Assistant Professor/Research Associate
Neighborhood Living Project
Specialized Training Program
College of Education
University of Oregon
Eugene, OR 97403

Phone (503) 346-2470/Fax (503) 346-5517

The Neighborhood Living Project's (NLP) mission is to improve the lives of transition age youth and other individuals with severe intellectual disabilities who live in community residences. The NLP's current research is focused in two areas: enhancing the social relationships of individuals with severe intellectual disabilities by improving their social networks, social integration, social support, and stability of social relationships; and facilitating and honoring the preferences and choice making of individuals with severe intellectual disabilities.

Since 1981, the NLP has helped over three hundred residential providers in Oregon and elsewhere to implement the Valued Outcomes Information System (VOIS). VOIS is a system that ensures residential services are planned, provided, and internally evaluated based on service outcomes valued by participants and their families. VOIS provides information about the degree to which the valued outcomes are experienced by participants. Providers use this information to improve the congruence between the lifestyles preferred by participants and the lifestyles they actually lead.

The NLP is a project within the Specialized Training Program, a research and development unit within the Division of Special Education and Rehabilitation of the University of Oregon's College of Education. The United States Department of Education's Office of Special Education Programs, the National Institute on Disability, Rehabilitation and Research, and Oregon's Office of Developmental Disability Service funds the NLP.

The NLP began in response to a request from the U.S. Department of Education for projects to develop, implement, evaluate, and communicate about models for achieving the deinstitutionalization and community integration in normalized, nonsegregated environments for children and youth with severe handicaps. A complete list of materials and more information is available by contacting Steve Newton, Assistant Professor/Research Associate, at (503) 346-2470.

PROJECT: RESCUE

A project that provides and accesses services for mothers with disabilities

Area Served: Georgia

Contact: Mary Yoder, Director
Project: RESCUE
Retarded Citizen/Atlanta, Inc.
215 Lakewood Way SW
Atlanta, GA 30315

Phone (404) 622-5343/Fax (404) 622-6575

Providing quality service to people regardless of income level, sex, or parental status is a challenge for the disabilities field. Project: RESCUE has met this challenge by assessing needs of, and providing services for, people with little money, especially single mothers with mental retardation.

An assessment and planning team consisting of Project: RESCUE staff, and whomever the consumer selects, surveys the consumer's needs. Team members look for natural supports and training opportunities to meet those needs.

Project: RESCUE functions primarily to connect people with resources through direct personal contact and assistance. In a few circumstances the project also provides services such as supported employment, training, and residential services. Case management is provided for all clients. The project looks at each family or person individually. Goals for people range from increasing reading and math skills to increasing community connections.

Retarded Citizen/Atlanta, a private, nonprofit agency contracting with the state of Georgia's Office of Mental Retardation operates Project: RESCUE. State and Federal grants, the United Way, and revenues generated internally provide funding. Annual costs are approximately one million dollars, half of which is funded through Medicaid.

Mary Yoder, Director, Project: RESCUE, feels the program has been successful in that it has aided consumers in being reunited with their children, owning their own homes, and getting jobs in the community. She see challenges for her consumers in limited housing for people with little money and other challenges of poverty. She has information available on Project: RESCUE and can be contacted at (404) 622-5343.

FAMILY SUPPORT ADVISORY COUNCILS

Volunteer regional councils that assure quality

Area Served: Louisiana

Contact: Patsy Davies
Project Consultant
1240 Aberdeen Ave.
Baton Rouge, LA 70808

Phone (504) 343-5974

Louisiana has legislated quality assurance methods for its Community and Family Support System which include regional and state Advisory Councils. Currently these Family Support Advisory Councils look at quality and implementation issues for the cash subsidies from the Family Support Program component of the system. However, plans are in place to expand the focus of these councils to other services within the Family Support Program as expansion funds are secured.

Formed in Fall 1992, these councils have begun to help with outreach, documentation, and implementation issues. Since Council members are themselves parents of children with disabilities, the councils provide for networking and advise for parents learning to access services. A three hour training and orientation program has been developed to assist the Councils in their work.

Issues that are statewide in nature are brought by regional councils to the state Family Support Advisory Council. Although the Councils have no formal authority, both state and regional Advisory Councils do bring issues to light and provide assistance.

Recently two parents were hired part-time as liaisons between the Councils and the Community and Family Support System Task Force, which oversees and implements the entire Community and Family Support System Plan. Council seats, however, are unpaid volunteer positions.

For more information contact Patsy Davies, Project Consultant to the Developmental Disabilities Council, at (504) 343-5974.

COMMUNITY CAPITAL ASSISTANCE HOUSING PROGRAM

A program that assists people to rent or own their own home

Area Served: Ohio

Contact: Jennifer Johnson
Ohio Department of Mental Retardation/Developmental Disabilities
35 East Chestnut Street, 5th Floor
Columbus, OH 43215

Phone (614) 466-7208/Fax (614) 644-6676

Persons with developmental disabilities may enjoy opportunities to exercise choice in where they live and with whom, and to exercise control of their own homes through Ohio's Community Captial Assistance Housing Program (CCAHP). Since 1989, CCAHP has assisted Ohioans with developmental disabilities to rent, and sometimes own, their own homes. Mandated independence of housing agencies from residential service providers, with separation of housing and services expenditures, enables consumers to change service providers while remaining in their homes.

The Ohio Department of Mental Retardation and Developmental Disabilities (MR/DD) manages the program, which is funded by sale of municipal bonds. Participating counties select and contract with non-profit corporations to purchase and manage the houses for a fixed fee, with the state MR/DD agency providing or guaranteeing mortgage funding on a case-by-case basis. Residents with developmental disabilities typically pay rent, maintenance, and operating costs with Supplemental Security Income (SSI) or other income. When the mortgage is fully paid, the ownership of the home may, in certain cases, be transferred to the residents of the home.

The program, which continues to expand, now provides typical housing for over 340 persons with developmental disabilities in the majority of Ohio's counties. Annually, more than 7 million dollars is budgeted for this program.

Further information, including a written summary of the program, may be obtained by writing to or phoning Jennifer Johnson at (614) 466-7508.

RESIDENTIAL DEVELOPMENT

A regional process that provides consumer choice of service providers

Area Served: Connecticut DMR Region 5

Contact: Tom Meehan, Director of Community Services
DMR Region Five
104 South Turnpike Road
Wallingford, CT 06492

Phone (203) 294-5043/Fax (203) 294-0220

It is commonly believed that allowing people with developmental disabilities to choose who will provide them services creates the kind of competition among service provider agencies that is essential to improving service quality. Connecticut Department of Mental Retardation, Region Five, (Region Five) has been working to test this belief by offering people with developmental disabilities entering into supported living arrangements the opportunity to select among provider agencies.

Region 5 began implementing Residential Development in 1992 with nineteen people seeking supported living arrangements. These people were profiled with the aid of their case managers and these profiles were distributed to area provider agencies at a regional conference. Provider agencies that desired to serve particular individuals made such an indication to Region Five. Region Five then distributed to consumers profiles of provider agencies seeking to serve these consumers. Consumers and their families then set about to examine and interview potential agencies and selected the agency that best met their needs.

Some difficulty was incurred in time delays and confusion by consumers. Overall, however, families and consumers have found the process to be positive, and Region Five has seen a decrease in the number of consumers reporting they are dissatisfied with services. Tom Meehan, Director of Community Services, noted that provider agencies are promising an increased level of service during the interview process, and therefore must follow through with these promises to meet consumer expectations. He also noted that additional costs to Region Five have been minimal. For more information call Tom Meehan, Director of Community Services, at (203) 294-5043.

Best Practices

BEST PRACTICES FORUMS

A forum to communicate quality practices

Area Served: Arizona

Contact: Kathy Sweeney or John Cunningham
Department of Economic Security
Division of Developmental Disabilities
Quality Advocacy Unit
P.O. Box 13178
Tucson, AZ 85732

Phone (602) 628-6800/Fax (602) 628-6809

A place for open exchange among stakeholders including consumers, parents, providers, and state employees of ideas, theories, and opinions on a variety of topics concerning developmental disabilities is provided through the Best Practices Forums.

These regional forums are held four times a year in a neutral environment such as a public library. A panel of about five people facilitate the two to four hour long forums. Eighty to 160 people ask questions and offer comments to the panel. A provider focus group sets forum agendas. Ideas for forums usually come forward when a provider has a successful practice to be shared. The tone of the forums, therefore, is positive.

The goals of these forums are to communicate good ideas and to plant seeds for quality practices in the developmental disabilities field. Additionally, the forums bring together people who hold different perspectives. In many cases this has resulted in participants gaining new insight and empathy for opposing points and views.

Best Practices Forums began in January of 1992 as an outgrowth of provider focus groups. Arizona's Department of Economic Security loosely manages the forums, which operated without direct funding. However, the Department is considering ways to give participants, particularly parents and consumers, per diem pay for attendance at forums.

For more information, contact Kathy Sweeney or John Cunningham at (602) 628-6800.

BEST PRACTICES IN OREGON

A manual describing exemplary practices across Oregon

Area Served: Oregon

Contact: Darla Wilson/Meredith Brodsky
Paradigm Systems
P.O. Box 967
Salem, OR 97308-0967

Phone (503) 363-8609/Fax (503) 378-1979

The *Best Practices in Oregon* manual, developed and written by Paradigm Systems, is intended to briefly describe a variety of approaches being taken by service providers and advocates to improve the quality of services to persons with developmental disabilities. The programs described in the manual are currently operating in Oregon. They were nominated by service providers, case managers, parent, advocates, and state agency personnel not employed by the nominated agencies. The 1991 *Best Practices in Oregon* manual (published in 1992) included 34 exemplary practices. It is well written and readers will find it easy to find information of interest to them.

Programs nominated for inclusion in *Best Practices in Oregon* and were contacted by Paradigm Systems staff for telephone interviews about the practices. In these interviews, programs were verified as an exemplary practices and program information needed for description was gathered. A draft description was then written and forwarded to the agency for review and editing.

The purpose of the Best Practices in Oregon project is to stimulate consideration and implementation of innovative approaches to enhancing the quality of services for people with developmental disabilities in Oregon. The manual serves as a source of referral to agencies that have identified new ways of responding to the challenges of providing high quality community services to persons with developmental disabilities. Funding for Best Practices in Oregon comes from a portion of the Continuous Quality Improvement Project that is funded by the Oregon Mental Health & Developmental Disability Services Division. To date, approximately 1000 copies of Best Practices in Oregon have been sent out by Paradigm Systems.

Paradigm Systems intends to update *Best Practices in Oregon* periodically. For more information, or to order a copy of Be*st Practices in Oregon*, contact Darla Wilson, M.A. or Dr. Meredith Brodsky, Paradigm Systems, at (503) 363-8609.

NEKTON BEST PRACTICES MANUAL

Forums and manuals of innovative practices initiated by staff

Area Served: Minnesota

Contact: Peter (Skip) Sajevic, President
Nekton, Inc.
One Griggs Midway
1821 University Avenue
St. Paul, MN 55104-2800

Phone (612) 644-7680/Fax (612) 643-6777

Developing mechanisms for sharing creative ideas to resolve problems and improve services is vital in assuring quality in services for people with developmental disabilities. Affirming direct service staff for their creative activities and commitments is also important to their professional development and tenure. Nekton, Inc. does this through agency best practices forums and dissemination of a best practices manual.

Nekton forums on best practices are an established agency program, held as part of all-agency staff meetings. The manual identifies examples of best practices in supporting someone with developmental disabilities in individual opportunities, achievements, and accomplishments. Nekton compiles these descriptions of best practices into a best practices manual and shares them among all agency staff. The manual is an anecdotal guide to creative practices that focus on serving people, and not the agency.

Submissions have varied in their complexity, scope and focus. One example described a process that aided an individual in joining a church choir. The successful practice eventually lead to the staff member withdrawing from the activity, as community members began aiding the individual in getting to choir practices

For a copy of Nekton's *Best Practice Manual* or information contact Skip Sajevic, President, at (612) 644-7680. The fee of $5.25 covers printing and postage charges.

Quality Assurance in Community Supported Living Arrangements Programs

Medicaid waiver programs exist in virtually every state, providing services in community settings to persons with mental retardation and related conditions who would otherwise require ICF-MR or nursing home care. While viewed by states as offering an attractive alternative to long-term institutional care, greater flexibility to individualize services and a waiver of need for institutional care as an eligibility requirement have long been sought by a number of states as needed improvements in Medicaid waiver services.

In 1990 Congress added Section 1930 to the Social Security Act to allow eight states to provide Community Supported Living Arrangements (CSLA) to Medicaid-eligible persons with mental retardation and related conditions. In many ways similar to the Medicaid waiver programs CSLA provides states with greater flexibility in service provision and permits more specific targeting of services to eligible groups and geographic areas within a state. Unlike the Medicaid waiver it does not require that ICF-MR or nursing home level-of-care need be determined for eligibility. In a manner much more specific than the Medicaid waiver, but still permitting a high degree of state flexibility and control, CSLA requires each state to develop its own quality assurance program within areas defined by federal standards.

The eight states selected to provide CSLA (CA,CO,FL,IL,MD,MI,RI,WI) have varied in their target populations, projected numbers of recipients, services to be included and other factors. However, the states share a common perception of the CSLA option as an opportunity to serve in different ways unserved or underserved groups. The CSLA program offers participating states the potential to enhance quality of services by integrating a number of programmatic elements which consumers, advocates, providers and other professionals have argued are necessary for effective quality assurance and enhancement.

The descriptions of state programs that follow outline the approaches being taken to quality assurance in the CSLA programs.

QUALITY ASSURANCE FOR CSLA-CALIFORNIA

Area Served: California

Contact: Julia Mullen
Adult and Supported Living Services
Department of Developmental Services
1600 9th Street
Sacramento, CA 95814

Phone (916) 654-2426/Fax (916) 654-3641

California's Community Supported Living Arrangements (CSLA) program is designed to be highly consumer centered in its approach to quality assurance and enhancement. In addition to the more traditional efforts by state, regional, and local authorities to positively affect service quality through periodic inspection and review, California has incorporated three significant new elements within its CSLA program.

The Consumer Bill of Rights is central to planning, providing and monitoring CSLA services to Californians with developmental disabilities. It assures consumers the right to choice, dignity, respect, success, involvement in development of their Individual Service Plans and the power to say "No" in matters affecting their lives. Assurances include maximum consumer control of the use of CSLA dollars, including the right of the individual consumers to "hire and fire" their direct service providers and provider agencies.

Area Boards, funded by the Developmental Disabilities Council, operate Community Monitoring Teams (CMT) in each state region participating in CSLA to survey the satisfaction and quality of life of individual consumers. One Area Board contracts with a citizen advocacy agency to act as a CMT. More typically, CMTs are organized by Area Boards using a "friendship model," organizing teams of persons having positive relationships with the consumers whose circumstances and satisfaction they monitor. Area Boards encourage CMT involvement in a variety of ways through such activities as surveys of consumers' families and friends to find CMT volunteers, and sponsorship of social mixers for consumers and team members, with individual consumers choosing CMT members from persons they come to know.

Each consumer develops from the community a Circle of Support, an informal personal support network. Members of an individual network may perform various functions responsive to the consumer's needs and preferences, including helping in development of the consumer's Individual Service Plans, engaging in leisure activities with the consumer, and becoming a trained advocate for the consumer.

More information and a variety of CSLA program materials may be obtained by contacting Julia Mullen at (916) 654-2426.

QUALITY ASSURANCE FOR CSLA-MARYLAND

Area Served: Maryland

Contact: Hal Franklin, Assistant Director
Statewide Programs
Developmental Disabilities Administration
Department of Health and Mental Hygiene
201 West Preston Street, Fourth Floor
Baltimore, MD 21201

Phone (410) 225-5600/Fax (410) 225-5850

Health, safety, choice, empowerment, community integration, and consumer happiness are the primary aspects of daily living targeted by Maryland's CSLA quality assurance program. Maryland approaches quality assurance in these areas through a variety of approaches.

A cornerstone to Maryland's quality assurance approaches are the CSLA consumer empowerment rights. Examples are the right to terminate the provider agency and the right to review and revise the Individual Service Plan (ISP) at any time and for any reason. Friends and family of the consumer may also call for an ISP review at any time.

Maryland's Quality Assurance Review Committees (QARCs) are a primary mechanism for monitoring individuals' quality if life and service. Consumers, consumers' friends and families, and CSLA providers make up these committees. Some committees are focused on people served by a single provider, while others may focus on people served by several provider agencies. Teams formed from committees visit each consumer at least twice a year. Team members are nominated by individual consumers and attend to the services specifically provided to individuals, assessing consumer satisfaction with services, health and safety. Members make reports to the general QARC, who distribute reports to relevant parties, including providers, who must respond to suggestions for change, as well as to regional and state agencies.

An Advisory Committee made of persons from various constituencies, has also been developed to advise Maryland's Developmental Disabilities Administration (DDA) staff of CSLA program quality. This committee is autonomous from DDA, has no formal power, and is intentionally designed to be informal and advisory in nature.

Hal Franklin, Assistant Director, may be contacted for more information at (410) 225-5600.

QUALITY ASSURANCE FOR CSLA-MICHIGAN

Area Served: Michigan

Contact: Judy Webb
Office of Federal Liaison & Entitlements
Department of Mental Health
Sixth Floor, Lewis Cass Building
320 South Walnut
Lansing, MI 48913

Phone (517) 335-4078/Fax (517) 335-6775

Michigan's Community Supported Living Arrangements (CSLA) uses the philosophy of assisting people with disabilities to live like others in the community as a guide for quality assurance. In Michigan's CSLA Consumer Satisfaction Assessment Program consumers directly assess the impact of the supports they receive on their quality of life.

Michigan uses its Consumer Satisfaction Assessment process to obtain feedback from consumers about CSLA supports and services. Local sites are required to make this process available to consumers four times a year. A Community Monitoring Board at each site creates assistive mechanisms to help consumers complete a five-page questionnaire. Community Monitoring Boards are made up of consumers, family members and other person who do not represent service providers. Consumers may complete the interview via telephone, mail, or in-person; can choose who conducts the interview, such as a friend, neighbor, family member, advocate, or can select from a pool of volunteers; or may also choose to not answer any or all of the questions.

The aggregate report from this process is shared with the Consumer Monitoring Boards, the Governing Board, and twice a year, with the State. Neither the completed questionnaire or the raw data is shared with service providers or the Qualified Human Service Professional (QHSP)/case manager. Only urgent concerns are communicated to the QHSP.

Responsible Lead Agencies (RLAs) also participate in quality assurance. They operate outreach, intake, evaluation, individual support plans, provider screens, and support coordination. RLAs provide quarterly consumer reviews and surveys of subcontractors.

Judy Webb, Department of Mental Health, feels an important aspect of Michigan's CSLA program is that it is locally driven and flexible. She expects to see programs develop that are unique to their local areas. For more information contact Judy Webb at (517) 335-4078.

QUALITY ASSURANCE FOR CSLA-RHODE ISLAND

Area Served: Rhode Island

Contact: Sue Babin, Administrator
Division of Developmental Disabilities
Department of Mental Health, Mental Retardation, and Hospitals
600 New London Avenue
Cranston, Rhode Island 02920

Phone (401) 464-3234/Fax (401) 464-3570

Rhode Island's plan to assure and enhance quality in its Community Supported Living Arrangements (CSLA) program involves efforts by a variety of organizations and individuals including the state Division of Developmental Disabilities (DDD), the state Developmental Disabilities Council, Consumer/Parent Monitoring Boards, CSLA provider agencies, and consumers themselves. The state Division of Developmental Disabilities has developed materials and procedures addressing issues of human rights, service outcomes, allegations of abuse and provider compliance with CSLA standards. DDD will make unannounced visits to CSLA programs, conduct annual quality assessment reviews with individual consumers and provide technical assistance to CSLA providers.

The state Developmental Disabilities Council has contracted with an outside agency to conduct annual evaluations to determine the effectiveness of CSLA services as an alternative to traditional service systems and to measure consumer satisfaction. Three Consumer/Parent Monitoring Boards evaluate the involvement in decision making and satisfaction with supports received of each CSLA consumer within their respective regions. Consumer/Parent Monitoring Board activities are closely tied to the Individual Support Plan review process.

The state CSLA Advisory Committee is composed of persons initially brought together to design the CSLA application, with the intended benefit of optimizing information dissemination about CSLA in Rhode Island.

CSLA quality assurance in Rhode Island is funded by state and federal agencies and with a $15,000 training and consultation grant from the state Developmental Planning Council. For more information contact Sue Babin at (401) 464-3234.

QUALITY ASSURANCE FOR CSLA-WISCONSIN

Area Served: Wisconsin

Contact: Ken Golden, Program Manager
Developmental Disabilities Office
Community Services Division
Wisconsin Department of Health and Human Services
1 West Wilson Street, P.O. Box 7851
Madison, WI 53707

Phone (608) 266-1520/Fax (608) 266-0036

Wisconsin's goal for its CSLA quality assurance program is to increase monitoring responsibility in local areas through less state monitoring and more state technical assistance. Given the relatively high level of county control over services in Wisconsin this provides for a better integration of quality assessment, service development and service authorization.

The state certifies CSLA service provider agencies and surveys them annually. Additionally, state staff make visits to consumers and families to assure health and safety, contacting at least 25% of all program participants. Surveyors use the Review Guide, that includes examining consumer empowerment and quality-of-life issues.

Case managers also provide ongoing monitoring of services and individual well-being. In Wisconsin, case management does not necessarily need to be conducted by a professional. Consumers are free to choose an unpaid family member to coordinate services. The state, however still assigns a professional case manager to act as a government contact person and consultant to the consumers.

Local monitoring boards conduct site visits and consumer interviews to assess consumer satisfaction with CSLA services and report fundings annually to the state Developmental Disabilities Office. The state prepares an annual report summarizing the reports of local monitoring boards. Robin Cooper, Program Manager, says the reports from the local monitoring boards have been very positive. Consumers and local monitoring board members like CSLA services. She notes particular enthusiasm from board members. She also indicated that Wisconsin is considering options to expand authority for local monitoring boards for quality assurance and to enable the state to more actively support quality enhancement through technical assistance.

For more information contact Ken Golden, Program Manager at (608) 266-1520.

QUALITY ASSURANCE FOR CSLA-FLORIDA

Area Served: Florida

Contact: Linda Davis, Director
Supported Living Project
Department of Health & Rehabilitation Services
1317 Winewood Boulevard, Building 5, Room 210
Tallahassee, FL 32301

Phone (904) 488-3673/Fax (904) 922-6456

CSLA in Florida provides Medicaid eligible people in supported living arrangements with the services of supported living coaches to assist them in developing and using community living skills. This service has a three part quality assurance program.

First, support coordinators (case managers) aid consumers in choosing among service providers. Once services begin they make quarterly visits to the consumer and coach to review the supported living plan and address any gaps in services, along with reviewing housing conditions using Housing and Urban Development (HUD) standards. Support coordinators are also required to make at least monthly telephone contacts with consumers.

Second, District Developmental Disabilities Offices conduct annual unannounced visits to providers of services to monitor compliance with the providers' certification application and assure monitoring boards have been set up for each consumer. If providers are out of compliance, or there are unresolved issues, District Offices will require providers to develop a plan of corrective action. Administrative sanctions and decertification could also be imposed.

Third, consumers choose members to be on their volunteer monitoring teams. These teams may not include direct-care workers from the consumer's service provider organization. Team members examine planning and service delivery, as well as the extent to which the consumer's desired quality of life outcomes have been achieved. Teams also look at consumer benefits from, and satisfaction with, supports and services received.Teams reports are sent to the state monitoring board and the state district office.

For a copy of *A Handbook for Monitoring Quality of Life* and its accompanying *Technical Assistance Booklet for Quality Assurance Specialists* or other information on Florida's CSLA quality assurance program contact Linda Davis, Director, at (904) 488-3673.

QUALITY ASSURANCE FOR CSLA-ILLINOIS

Area Served: Illinois

Contact: Melissa Wright, Bureau Chief
Illinois Department of Mental Health & Developmental Disabilities
William Stratton Building, Room 405
Springfield, IL 62765

Phone (217) 524-2515/Fax (217) 782-9535

Statewide systems of independent service coordination and volunteer monitoring are central to the process of assuring and enhancing service quality in Illinois' Community Supported Living Arrangements (CSLA) program.

Independent service coordinators are a recent innovation on a statewide basis in Illinois. Under this system, activities often performed by case managers in other states are the responsibility of independent service coordinators in Illinois. Independent service coordinators are employed by private agencies that may not provide, or be related to agencies that provide, other services to persons with developmental disabilities.

Creation of a statewide network of trained volunteer advocates, coordinated in each of the three areas encompassing the state, is an innovation specific to the CSLA program. Volunteer advocates meet annually with each consumer who has consented to be interviewed to complete a 10 question consumer satisfaction survey. Each volunteer is accompanied and assisted as needed by the consumer's independent service coordinator. Completed surveys are sent to the area coordinator to be reviewed and forwarded to the Illinois Department of Mental Health & Developmental Disabilities for summary and analysis. Survey data is used in planning state technical assistance and training on both regional and statewide bases. If, in the survey process, need for action to protect a consumer is identified, the volunteer may contact appropriate state authorities directly for immediate intervention. Technical assistance is provided to CSLA providers by state staff.

Illinois has published a user-friendly consumer handbook and a technical assistance guide for both consumers and service providers. Arc of Illinois will administer the citizen advocacy project for CSLA recipients.

For materials and further information contact Melissa Wright at (217) 524-2525.

QUALITY ASSURANCE FOR CSLA-COLORADO

Area Served: Colorado

Contact: Heidi Cunningham, Program Manager
Program Quality
Division for Developmental Disabilities
3824 West Princeton Circle
Denver, CO 80236

Phone (303) 762-4581/Fax (303) 762-4300

Colorado has designed a multifaceted approach to quality assurance for CSLA that distributes responsibility for quality assurance among many stakeholders. Provider agencies, monitoring boards, Community Centered Boards, and the Division for Developmental Disabilities conduct various quality assurance activities that intentionally overlap.

Colorado's CSLA program is currently in its second year with nine of its twenty Community Centered Boards (CCBs) providing CSLA. These nonprofit local boards contract with the state of Colorado to provide or purchase services for individuals with developmental disabilities in their geographic service area. Local monitoring boards have been set up under CCBs providing CSLA to review CCB practices in monitoring health and well-being of participants, review CSLA minimum protection compliance, evaluate agency practices in resolving consumer complaints, assess consumer satisfaction with services, review the extent to which consumers are offered real choices and assisted to make increasingly responsible decisions. Monitoring boards are required to meet at least quarterly, survey agencies at least annually, and hold open forums annually.

The Division developed A Training Manual for Monitoring Boards to give board members an overview of CSLA, their responsibilities, and suggestions for ways to fulfill those responsibilities. This manual also includes information on organizing volunteer boards.

The Division also conducts agency reviews annually, and within 90 days of agency CSLA approval. The Division is finding CSLA flexibility is resulting in creative individual plans and that consumers are particularly pleased about their increased control over their own services.

Other sources of CSLA quality assurance in Colorado are: case management monthly monitoring; provider agency individualized monitoring plans; and a systematic evaluation of the CSLA program that will be conducted within the first two years. For more information or materials contact Heidi Cunningham, Program Manager, at (303) 762-4581.

QUALITY RELATED READINGS

STANDARDS AND MEASUREMENTS

Accreditation Council on Services for People with Disabilities. (1993). *Outcome based performance measures*. Landover, MD: Author.

Avai ıble for about $35 from the Accreditation Council on Services for People with Disabilities, 8100 Professional Place, Suite 204, Landover, MD 20785-2225, phone (301) 459-3191.

The Accreditation Council's manual describes thirty outcomes identified by people with disabilities and forms the Accreditation Council's quality enhancement and accreditation program. A profile in an earlier part of this book depicts the Outcome Based Performance Measures (See ACD-Outcome Based Performance Measures).

Allen, Shea, and Associates. (1993). *Final report on quality assurance assessment instruments*. Napa, CA: Author.

Available from Allen, Shea, and Associates for approximately $9.95. Contact them at: 1040 Main Street, Suite 200B, Napa, CA, 94559, phone (707) 258-1326.

The Colorado Division of Developmental Disabilities contracted with Allen, Shea, and Associates to review seventy-two measurement instruments in quality assurance measurement as part of Colorado's Program Assessment and Review (COPAR). This sourcebook presents profiles of both COPAR and Allen, Shea, and Associates' *Final Report* (see COPAR and Quality Measurement Instrument Review).

Commission on Accreditation of Rehabilitation Facilities. (1990). *Standards manual for organizations serving people with disabilities*. Tucson, AZ: Author.

Available from the Commission on Accreditation of Rehabilitation Facilities, 101 North Wilmot Road, Suite 500, Tucson, AZ 85711, phone (602) 748-1212.

This manual includes standards to assist service providers in staff training, service planning and development, program evaluation and improvement, and preparation for a voluntary survey leading to accreditation.

O'Brien, J., Lyle O'Brien, C. & Schwartz, D. (Eds.). (1990). *What can we count on to make and keep people safe*? Lithonia, GA: Responsive Systems Associates.

Available through the Pennsylvania Developmental Planning Council, 569 Forum Building, Harrisburg, PA 17101, phone (717) 787-6057.

What can we count on to make and keep people safe? contains excerpts of discussions and writings by participants in the Pennsylvania Developmental Disabilities Planning Council 1990 annual retreat. The report contains perspectives on creating effective safeguards for people with developmental disabilities. This report contrasts the personal security approaches of administrative regulations and legal advocacy with lifesharing, and other personal commitments.

Schalock, R., Keith, K. & Hoffman, K. (1989). Quality of life: Its measurement and use. *Mental Retardation, 27*, 25-31.

Available from American Association on Mental Retardation in *Mental Retardation*, 1719 Kalorama Road NW, Washington, DC 20009, phone 1 (800) 424-3688.

This article proposes a quality-of-life index that may be used the index either as an outcome measure or as a criterion for the goodness-of-fit between people and their environments.

Rowitz, L. (Ed.). (1992). Symposium on compliance and quality in residential life. *Mental Retardation, 30* (3).

Available from the American Association on Mental Retardation in *Mental Retardation*, 1719 Kalorama Road NW, Washington, DC 20009, phone 1 (800) 424-3688.

This issue of *Mental Retardation* is devoted to discussing the search for balance between protections that bureaucratic regulations attempt to provide for people with mental retardation, and the efforts to support them. Writings and commentaries are included by Senator Edward Kennedy, James Gardner, Elizabeth Boggs, Steve Taylor, and others.

QUALITY MANAGEMENT

Albin, J.M. (1992). *Quality improvement in employment and other services: Managing for quality through change*. Baltimore, MD: Paul H. Brookes.

This book is written for staff of agencies that provide supported employment for people with severe disabilities. It is relevant, however, to a wide range of service provider agencies. Its focus is how to apply quality improvement approaches developed in business to services for people with severe disabilities living in communities.

Brodsky, M., & Wilson, D. (1992). *Continuous quality improvement in Oregon's programs for people with developmental disabilities*. Salem, OR: Paradigm Systems.

Available from Paradigm Systems, PO Box 967, Salem, OR 97308-0967, phone (503) 363-8609.

This publication describes the application of total quality management approaches to small programs for persons with developmental disabilities. It follows the quality philosophy of W. Edwards Deming, and uses a seven-step system for developing and implementing an improvement plan. This sourcebook also contains a profile of Oregon's statewide program (See Oregon System of Continuous Quality Improvement).

Crosby, P. (1980). *Quality is free. The art of making quality certain.* New York, NY: Plume.

Available for about $7 through Penguin Books USA, 375 Hudson Street, New York, NY 10014 or at local book stores.

Philip Crosby discusses methods he considers practical, productive, and cost effective in managing and improving quality. He takes a long-term quality focus, and stresses that monitoring for problems after-the-fact is more costly than developing quality systems up front. Crosby's book includes his Fourteen-step Quality Improvement Program and his Quality Management Maturity Grid.

Osborne, D., & Gaebler, T. (1993). *Reinventing government. How the entrepreneurial spirit is transforming the public sector.* New York, NY: Plume.

Available for about $13 through Penguin Books USA, 375 Hudson Street, New York, NY 10014, or at local book stores.

Reinventing Government outlines an approach to cutting taxes, improving public services, and moving away from bureaucracy. It includes profiles of existing entrepreneurial governments and the ten principles on which the authors consider them to be constructed.

Sluyter, G., & Mukherjee, A. (1993). *Total quality management. A paradigm for the '90s. Total quality management for mental health & mental retardation services.* Annandale, VA: American Network of Community Options and Resources (ANCOR).

Available through ANCOR, 4200 Evergreen Lane, #315, Annandale, VA 22003, phone (703) 642-6614.

Sluyter and Mukherjee's book describes the application of total quality management for organizations that provide services for people with disabilities. It leads the reader through the processes and practices developed by W. Edwards Deming, and depicts how they may be applied to human services.

Walton, M. (1988). *The Deming Management Method.* New York, NY: Perigee Books.

The Deming Management Method reviews the work by W. Edwards Deming, quality management consultant, with emphasis on his Fourteen Points. It also profiles the quality methods of various organizations that have implemented Deming's techniques. It is an excellent book upon which readers can build knowledge of organizational quality concepts.

QUALITY ENHANCEMENT AND DEVELOPMENTAL DISABILITIES

Bradley, V., & Bersani, H., Jr. (1990). *Quality assurance for individuals with developmental disabilities: it's everybody's business*. Baltimore, MD: Paul Brooks.

Available through Paul Brooks Publishing, PO Box 10624, Baltimore, MD 21285-0624.

More than two dozen experts discuss quality assurance for persons with developmental disabilities in this book. Contributors include consumers, families, advocates, government personnel, academics and others.

Lakin, K.C., Prouty, R., Smith, G. (Eds.). (Summer, 1993). Quality assurance. *Impact. 6*(2).

A complimentary issue is available from Publications Office, Institute on Community Integration, 109 Pattee Hall, 150 Pillsbury Drive SE, Minneapolis, MN 55455, phone (612) 624-4512.

This entire issue of the quarterly journal *IMPACT* is devoted to the topic of quality assurance. It offers perspectives of leaders of innovative efforts to enhance service quality including Clarence J Sundram, Georgia Baddley, Jim Gardner, Kathleen Olson, and others.

Mount, B., & Zwernik, K. (1989). *It's never too early, it's never too late*. St. Paul, MN: Metropolitan Council.

Available through Minnesota's Bookstore, 117 University Avenue, Ford Building, Main Floor, St. Paul, MN 55155, phone (612) 297-3000. Currently the book costs $5.95 plus tax, shipping & handling.

This guidebook about personal futures planning is written for family members and advocates, but others will find it informative. It is intended as an introduction to the Personal Futures Planning process and not an instruction manual.

Prouty, R., & Lakin, K. (1991). *A Summary of States' Efforts to Positively Affect the Quality of Medicaid Home and Community-Based Services for Persons with Mental Retardation and Related Conditions (Report #34)*. Minneapolis, MN: University of Minnesota, Center for Residential Services and Community Living.

Available from Publications Office, Institute on Community Integration, 109 Pattee Hall, 150 Pillsbury Drive SE, Minneapolis, MN 55455, phone (612) 624-4512.

Robert Prouty and Charlie Lakin's report gives findings of a national survey of efforts by states to assure and enhance service quality for persons with mental retardation and related conditions receiving Medicaid Home and Community Based Services.

Smith, G., & Gettings, R. (1989). *Medicaid Home and Community Based Services for person with developmental disabilities.* Alexandria, VA: National Association of State Mental Retardation Program Directors.

Available from National Association of State Directors of Developmental Disabilities Services, Inc., 113 Oronoco Street, Alexandria, VA 22314, phone (703) 683-4202.

This report contains a description of quality assurance methods used in Medicaid Home and Community Based Services and Community Supported Living Arrangements in several states.

Schalock, R. (1990). *Quality of life.* Perspectives and issues. Washington D.C.: American Association on Mental Retardation.

Available through AAMR, PO Box 25, Annapolis, MD 20701, phone (301) 604-1340.

Twenty-two contributors to *Quality Of Life* offer chapters on various aspects of quality of life for people with mental retardation and developmental disabilities. The chapters are divided into four sections: personal perspectives; service delivery; assessment and measurement; and the future of quality of life concepts.

Schwartz, D. (1992). *Crossing the river: Creating a conceptual revolution in community and disability.* Brookline Press.

Available through Citizen Advocacy Forum, P.O. Box 86, Beaver, Pa 15009, phone (412) 775-4121.

In *Crossing the River*, David Schwartz discusses the conception of rediscovering the importance for all people of being and feeling embedded in a web of personal relationships. He points out the promise, potential and limits of this new direction, illustrated through a series of experiments in social policy connected with the Pennsylvania Developmental Disabilities Planning Council.

BEST PRACTICES AND STAFF DEVELOPMENT

Brodsky, M., & Wilson, D. (1992). *Best Practices.* Salem, OR: Paradigm Systems.

Available from Paradigm Systems, P.O. Box 967, Salem, OR 97308-0967, phone (503) 363-8609.

This manual provides brief descriptions of exemplary practices to support people with developmental disabilities in Oregon. This sourcebook contains a description of this manual and its development (See Best Practices in Oregon).

Wallace, T., Larson, S., & Hewitt, A. (Eds.). (Spring, 1992). Direct service staff training. *Impact. 5*(1).

Available from Publications Office, 109 Pattee Hall, 150 Pillsbury Drive SE, Minneapolis, MN 55455, phone (612) 624-4512.

This issue discusses direct care staff training, training delivery systems, training improvement models, and implications of various training approaches. Includes articles on training of direct service personnel in residential, vocational and educational setting. Also included are articles sharing the views of parents, persons with developmental disabilities, and direct care staff regarding training.

Hewitt, A., Larson, S., & Lakin, K. (1994). *A guide to high quality direct service personnel training resources*. Minneapolis, MN: Research and Training Center on Residential Services and Community Living, Institute on Community Integration (UAP), University of Minnesota.

Available from Publications Office, 109 Pattee Hall, 150 Pillsbury Drive SE, Minneapolis, MN 55455, phone (612) 624-4512.

The Research and Training Center on Residential Services and Community Living has published a resource guide that identifies and evaluates direct service staff training materials. Trainers of community direct service personnel working in community homes may find this sourcebook useful.

Nekton, Inc., (1993). *Best practices manual*. Saint Paul, MN: Author.

Available for about $5.25 from Nekton, One Griggs Midway, 1821 University Avenue, St. Paul, MN 55104-2800, phone (612) 644-7680.

Nekton, a private provider of services for people with developmental disabilities, created this brief manual. It includes stories about successful outcomes, and processes to facilitate these outcomes, for people with developmental disabilities. The manual places emphasis on individuals with disabilities rather than the organization. Stories depicted in the manual are both inspirational and informative. This sourcebook contains a profile of this project (See Nekton Best Practices Manual).

O'Brien, J., & Lyle O'Brien, C. (Eds.). (1992). *Remembering the soul of our work*. Madison, WI: Options in Community Living.

Available from Options in Community Living, 22 North Second Street, Madison WI 53704, phone (608) 249-1585.

Options in Community Living, a provider of services for people with developmental disabilities in Madison, WI, presents the products of a storytelling project of their staff. This sourcebook contains a profile of this project (See Story Writing).

O'Brien, J., & Lyle, C. (1987). *Framework for accomplishment*. Lithonia, GA: Responsive Systems Associates.

Available from Responsive Systems Associates, 58 Willowick Drive, Lithonia, GA 30038, phone (404) 987-9785.

Staff of organizations serving persons with disabilities may use the approach of *Framework for Accomplishment* to improve service quality. John O'Brien and Connie Lyle's method brings staff through active self-evaluation and problem solving by focusing on the life preferences and desires of individuals served by their organization. The focus is to elevate the understanding and appreciation of individuals, and to use available resources to improve the organizations's contributions to lifestyles desired by persons served. This sourcebook contains a profile of this project.

Gardner, J., & Chapman, M. (1993). *Developing staff competencies for supporting people with developmental disabilities*. Baltimore, MD: Paul H. Brooks.

This publication presents a basic course of self-guided instruction and self-evaluation in the concepts, attitudes and knowledge of value in assisting persons with developmental disabilities in community settings. Persons who provide services to persons with developmental disabilities may find a useful orientation.

COMMUNITY LIVING/SUPPORTED EMPLOYMENT

Hayden, M., & Abery, B. (Eds.). (1994). *Challenges for a service system in transition. Ensuring quality community experiences for persons with developmental disabilities*. Baltimore, MD: Paul Brooks.

Available through Paul Brooks Publishing, PO Box 10624, Baltimore, MD 21285-0624.

Numerous contributors to this book, including Charlie Lakin, Sheryl Larson, Robert Bruininks, and others, critically examine issues, research, and policies surrounding full community inclusion of individuals with developmental disabilities. The entire book is a useful guide for empowering people with disabilities and ensuring the quality of services that support them.

Kiernan, W., and Schlock, R. (Eds.). (1989). *Economics, industry, and disability. A look ahead.* Baltimore: Paul H. Brookes Publishing Company.

Available through Paul H. Brookes Publishing Co., PO Box 10624, Baltimore, MD 21285-0624.

Economics, Industry and Disability addresses the opportunities, challenges, and economic changes surrounding the supported employment movement for people with disabilities.

National Association for Private Residential Resources (Eds.). (1991). *Supported living* (Volumes 1 and 2). Annandale, VA: Author.

Available from the National Association of Private Residential Resources, 4200 Evergreen Lane, Suite #315, Annandale, VA 22003.

These volumes contain readings and bibliographies related to the supported living for people with developmental disabilities. They focus on the search for understanding, establishing, and maintaining quality of life as defined by individuals receiving supported living services. Contributors to *Supported Living* include John O'Brien, Jane Wells, Jay Klein, and others.

O'Brien, J. (1994). Down stairs that are never our own: Supporting people with developmental disabilities in their own home. *Mental Retardation, 32(1)*, 1-6.

Available from American Association on Mental Retardation in *Mental Retardation*, 1719 Kaorama Road NW, Washington, DC 20009, phone (800) 424-3688.

Also available from Responsive Systems Associates, 58 Willowick Drive, Lithonia, GA 30038, phone (404) 987-9785.

John O'Brien addresses choosing and controlling one's home environment in this article. He relates these concepts to the quality of life for persons with developmental disabilities.

Racino, J., Walker, P., O'Connor, S., & Taylor, S. (Eds.). (1993). *Housing, support, and community*. Baltimore: Paul H. Brookes Publishing Company.

Available through Paul H. Brookes Publishing Co., P.O. Box 10624, Baltimore, MD 21285.

This is volume two of the Community Participation series of books developed through the Center on Human Policy. It highlights efforts in communities to improve the quality of life for people with disabilities. This publication presents current strategies and unique ways of thinking about supporting people to live in their own homes and participate in their communities.

Smith, G. (1990). *Supported living: New directions in services to people with developmental disabilities*. (Community Management Initiative Series). Alexandria, VA: National Association of State Directors of Developmental Disabilities Services, Inc.

Available from National Association of State Directors of Developmental Disabilities Services, Inc., 113 Oronoco Street, Alexandria, VA 22314, phone (703) 683-4202.

Gary Smith's report describes emerging trends in supported living for persons with developmental disabilities including the goals, definitions of quality, and activities taking place in various states.

Smull, M., & Harrison, S. (1992). *Supporting people with severe reputations in the community*. Alexandria, VA: National Association of State Directors of Developmental Disabilities Services, Inc.

Available from the National Association of State Directors of Developmental Disabilities Services, 113 Oronoco Street, Alexandria, VA 22314, phone (703) 683-4202.

This handbook discusses how people receive severe reputations, how to plan with the individual around the individual's perception of quality in community supports, how to recruit and develop the supports needed to realize the individual's own desired lifestyle, and how to avoid the mistakes and abuses in providing supported living services.

HEALTH CARE

Pfaffinger, K., & Nelson, R. (1988). *Quality health care for persons with developmental disabilities: a guide for parents and other care givers.*

Available from Publications Office, Institute on Community Integration, 109 Pattee Hall, 150 Pillsbury Drive SE, Minneapolis, MN 55455, phone (612) 624-4512.

This publication is a practical guide to health care for persons with disabilities. It includes specific suggestions on a wide range of relevant health care topics.

Beegle, G., & Ramberg, J. *Health: An introduction to developmental disabilities*. Parsons, KS: Kansans Educating & Empowering Persons with Developmental Disabilities.

Available from KEEP/UAP, University of Kansas, P.O. Box 738, Parsons, KS 67357.

The University of Kansas created this publication as a curriculum module for training direct care staff on meeting the basic health care and special medical needs of persons with developmental disabilities.

General Accounting Office. (1990). *Quality assurance: A comprehensive, national strategy for health care is needed.* Gaithersburg, MD: Author.

Available from U.S. General Accounting Office, PO Box 6015, Gaithersburg, MD 20877.

The General Accounting Offices's briefing report on quality assurance focuses on health care systems. It provides several concepts, considerations and recommendations relevant to long-term care for persons with developmental disabilities.

Shelton, T., Jeppson, E., & Johnson, B. (1992). *Family-centered care for children with special needs*. 2d ed. Bethesda, MD: Association for the Care of Children's Health.

Available through the Association for the Care of Children's Health, 7910 Woodmont Avenue, Suite 300, Bethesda, MD 20814, phone (301) 654-6549.

Family-centered Care for Children with Special Health Care Needs presents eight components identified by parents and professionals as key elements of a family-centered multifaceted approach to health care. It defines each element and gives examples of family-centered approaches, programs, and policies.

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